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Young Children with Down's Syndrome

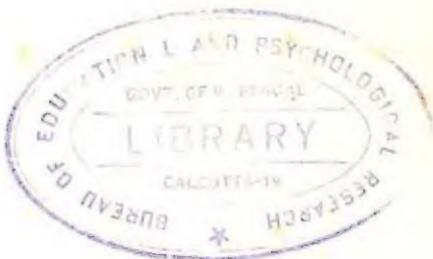
Janet Carr

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on Their Families

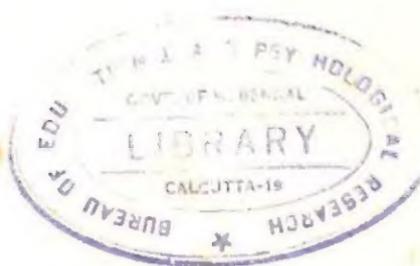


Young Children with Down's Syndrome

Their Development,
Upbringing, and Effect
on Their Families

JANET CARR PhD

Lecturer in Psychology,
Institute of Psychiatry, University
of London; Senior Psychologist,
Hilda Lewis House, Bethlem Royal
Hospital, London



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Introduction

The investigation reported here originated as part of a longitudinal study of the development of a group of babies with Down's Syndrome from a general population sample. For the first 18 months the study was carried out in association with Dr Valerie Cowie of the Medical Research Council's Psychiatric Genetics Research Unit, and from 1965 to 1969 under Professor Jack Tizard at the Department of Child Development, University of London Institute of Education, with the aid of a grant from the Medical Research Council.

The original aim was to study the early development of the baby with Down's Syndrome, to see whether there was a demonstrable deterioration in the rate of development, and if so, when this occurred, and to see whether the pattern of development was an orderly one. The project also provided an opportunity to study the development of children with Down's Syndrome brought up in different environmental conditions; to compare those children brought up in their own homes with those who were boarded-out in foster homes and institutions, and, among the home-reared children, to compare those from different social class groups.

It was also possible to study the effect that these handicapped children had on their families, and especially on their mothers; to consider the impact of the diagnosis when it was first given to the parents, and subsequently the effect of the growing child on their personal, family and social lives; and to explore the effectiveness of the help the mothers had had from the various medical, social and educational agencies. Much of this part of the study was carried out in co-operation with Drs John and Elizabeth Newson, whose well known studies of child-rearing practices in families of normal children are extensively referred to in this part of the book. They kindly allowed me to make use of the interview schedules they had devised for their own studies, and these, with some omissions and some adaptations to cover points of special interest on mentally handicapped children, formed the essential basis of this part of the project.

So the study falls into two distinct sections; first, that concerned with the development of the children and their performance at succeeding ages on tests; and second, that concerned with the effect on the family of a handicapped child.

A total of 54 babies with Down's Syndrome was seen at least once by the writer, and 45 continued in the study until 4 years old. Seven visits were paid by the writer to each child between the ages of 6 weeks and 4 years. The babies were given developmental tests at each visit, and at 15 months and 4 years the mothers were interviewed to explore the problems encountered by families with a child with Down's Syndrome.

A group of normal babies, matched for age, sex and social class, was visited and tested in the same way, and their mothers given the same interviews. The inclusion of the normal babies was thought essential, first to provide a constant frame of reference of average levels during developmental testing; and second in the family study to perform much the same function. Bringing up normal non-handicapped children is attended by numerous difficulties and problems, and we wanted to be sure that, in describing families of children with Down's Syndrome, we were not attributing difficulties that they experienced to the presence of a handicapped child that might have existed if the child had not been handicapped. By including the normal children we were able to see how many problems were to be expected in any average family, and what were the particular problems that the families with a child with Down's Syndrome encountered. In this way too we hoped we should be better able to identify the extra help and services that the families need.

I am indebted to the Medical Research Council for their financial support of the study and to Dr Valerie Cowie for introducing me to the project. I am most grateful to Dr Nancy Bayley for allowing me access to the unpublished form of her *Scales of Infant Development* and to Lady Jessie Francis Williams who coached me in their use. I would like to express my great gratitude to Drs John and Elizabeth Newson for allowing me to make use of their Guided Interview Schedules in the family study, and for the help they gave to this. I would like to thank Mrs Frances Good for her advice and assistance with the statistics; Dr Sheila Hewett who read the manuscript and whose own work is here liberally quoted; Dr Jacob Kahn for advice on genetics; and Miss Mary Hurford, Miss Olwen Davis and Miss Ann Brundrett for secretarial help. My most grateful thanks are due to Professor Jack Tizard for his guidance and support throughout the project and for his detailed criticism of the manuscript; without his help it is unlikely that the study would have survived to completion.

Finally I would like to thank all the parents and foster parents of the children, both those with Down's Syndrome and the controls, whose co-operation made this study possible.

1

Down's Syndrome—Implications of the Diagnosis

PREVALENCE AND LIFE EXPECTANCY

Down's Syndrome, or mongolism, was first described by John Langdon Down in 1866. Until that time the condition had not usually been recognized as distinct from other forms of mental subnormality. Almost certainly however it had existed long before that, possibly as far back as the seventh century (Brothwell, 1960) while some sixteenth and seventeenth century paintings have depicted infants with mongoloid features (Cone, 1968; Zellweger, 1968). However, Zellweger warns of the dangers of accepting this kind of pictorial evidence, pointing out that in one such painting the infant later became an admiral of the British Fleet. Richards (1968) suggests that mongolism may indeed have been a rarer disease in the past because of smaller populations and higher rates of infant and maternal mortality—in the mid-nineteenth century only 58 per cent of women survived to the age of 35 which, as this is the high-risk age for mothers of Down's Syndrome babies, would halve the incidence (Richards, 1968). More recently Goodman and Tizard (1962) have shown that there has been an increase in the number of children with Down's Syndrome surviving to school age and simultaneously a decline in the number of children with other forms of subnormality: comparing the survey of E. O. Lewis in 1925 and their own survey in 1962 they found that in the age group 7 to 14 children with Down's Syndrome had increased from 0.34 to 1.14 per 1,000, while other forms of subnormality had declined from 3.37 to 2.31 per 1,000*. Some factors, such as better training of the children and the decline in some diseases (such as syphilis)

* There is no evidence that the increase in the number of surviving cases of Down's Syndrome is due to a higher incidence at birth, and indeed there is some evidence that this has declined somewhat in recent years, probably due to a tendency for women to complete their families earlier (Stein *et al.*, 1973).

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predisposing towards mental handicap in children, may have contributed particularly to the latter difference; others, such as better living standards, improved care of mothers and babies, the advent of antibiotics and so on, may have at once contributed to the lower rate of damage in infants generally and to the increased chances of survival of those with Down's Syndrome. Certainly the child with Down's Syndrome is now less likely to die at an early age than he was even 30 years ago. The findings from four major studies together with those from the present study are shown in Table 1.1. They have been arranged as nearly as possible in chronological order with those from Carter (1958) Collman and Stoller (1963) split into two periods each, as the authors themselves presented the figures.

TABLE 1.1
Mortality Up to 1 Year in Children with Down's Syndrome

	Period studied	Sample size	Dead by 1 month (%)	Dead by 1 year (%)
Carter (1958)	1944-48	350 (approx)	38	66
Record and Smith (1955)	1942-52	217	26.5	54
Collman and Stoller (1963)	1948-52	355	—	35
Carter (1958)	1949-55	350 (approx)	22	40
Collman and Stoller (1963)	1953-57	374	—	27
Fabia and Drolette (1970)	1950-66	2,421	(7-27 days) 5.6	23.6
Present study	1963-68	79	11	16

Table 1.1 shows that there has been a steady decrease in mortality over the period covered. The one notable discrepancy concerns the slight rise in deaths before one month between the figures from Fabia and Drolette and those from the present study: this may be due, perhaps, to some missed deaths in the earlier study, since Fabia and Drolette report no deaths between 0 and 6 days, whereas in the present study, 5 of the 9 children dying by one month were dead by 4 days.

Other studies have shown evidence of increased life expectancy beyond the first year for children with Down's Syndrome; in 1929 it was 9 years, but by 1947 12 years (Penrose and Smith, 1966) and by 1963 18 years (Collman and Stoller, 1963). These figures are the average ages of deaths for the whole group, and of course include those dying at a very early age. The age to which some people with Down's Syndrome have lived has also steadily increased; in 1947, of 138 cases known to five local authorities only 6 per cent were over the age of 34 and none over 45 (Penrose, 1949); in Forssman's (1960) study, out of 1,267 patients in institutions 14 per cent were over the age of 34 and 5 per cent over 45. The oldest age to which a person with Down's Syndrome has been reported as surviving is 63 (Brothers and Jago, 1954; Forssman, 1960).

Several studies have shown mortality rates to be slightly higher in females

with Down's Syndrome than in males (Øster, 1953; Carter, 1958; Penrose and Smith, 1966; Fabia and Drolette, 1970). Record and Smith (1955) showed that this led to an increase in the proportion of surviving males with age, from 55.4 per cent at birth to 60.7 per cent at 5 years old. Hug (quoted by Record and Smith, 1955) found the opposite, that the mortality rate for males was higher, Forssman and Åkesson (1965) found mortality rates equal in the sexes, while Collman and Stoller (1963) found a significantly higher female mortality rate only in the first 6 months of life. In the present study of children up to 4 years old 13 of the 17 children who died were girls so in this very small sample there is some support for a higher mortality rate in females.

The incidence at birth of children with Down's Syndrome is overall about one in 700 (Penrose and Smith, 1966). The incidence found in a number of studies ranges from one in 520 to one in 873 (Penrose and Smith, *op. cit.*). Zappella and Cowie (1962) suggest that the true figure is nearer one in 557; in most cases incidence figures are derived from hospital records and even in hospital-born children, where the highest incidence is found, 16 per cent in their study were not diagnosed until the age of 6 months or older. Incidence at birth varies with the age of the mother: between 20 and 24 the mother's chance of having an affected child is one in 1,600; between 30 and 34, one in 880; between 40 and 44, one in 100; and after 45 one in 46 (Collman and Stoller, 1962). Birth order has no effect when the mother's age, which is also correlated with birth order, is allowed for, nor does paternal age have any detectable influence on the incidence of Down's Syndrome when maternal age is kept constant except in the rare case of G-G* translocations (Penrose and Smith, 1966).

CHROMOSOMAL ASPECTS

A major breakthrough in the understanding of the condition of Down's Syndrome came in 1959 when Lejeune, Gautier and Turpin showed that, while the cells of normal human subjects contain 46 chromosomes (23 pairs) the cells of Down's Syndrome subjects contain 47 chromosomes (22 pairs and 1 triplet). Down's Syndrome was thus shown to be associated with an additional chromosome. It is usually agreed among geneticists that the extra chromosome in Down's Syndrome is always of the same type, that is, identical with chromosomes of pair 21 in group G*, so Down's Syndrome is described as Trisomy G-21, and this form of the condition is found in approximately 90 per cent of all cases of Down's Syndrome (Scully, 1973). In some forms of Down's Syndrome the extra chromosome is fused to another chromosome belonging to either group D or G. This condition can

* The system of chromosomal classification referred to is that laid down in: Standardisation in Human Cytogenetics. Birth Defects. Original Articles Series II: 2, 1966. The National Foundation, New York.

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be, though is not always, inherited in families; the parents may be healthy but when their chromosomes are examined the cells of one parent may be found to contain 45 instead of 46 chromosomes. This is due to a DG or GG fusion thus reducing the chromosome complement in each cell from 23 pairs (46 chromosomes) to 21 pairs and 3 singlets (45 chromosomes). A person with this type of translocation is known genetically as a balanced heterozygote or as a carrier of a balanced translocation (DG or GG as the case may be). The mean age of mothers of these babies is not increased. With the DG balanced translocation the risk of giving birth to a child with Down's Syndrome is about 10 per cent if the mother is the carrier and is reduced to nearly 2 per cent if the father is the carrier.

The risk of a GG translocation carrier having an affected offspring is around 10 per cent irrespective of the sex of the parent (Hamerton, 1968). Where a parent is not a carrier for Down's Syndrome the condition usually arises as a result of an error during cell division. This can happen before, during or after the fusion of sperm and egg-cells (zygote formation). An error in cell division which arises after the zygote is formed may result in an individual whose cells are of two types: normal cells, and cells of the Down's Syndrome type, and in this case the condition is termed mosaicism. In such individuals the severity of the condition depends on the final distribution of the abnormal cells, which varies not only from individual to individual but also from tissue to tissue in one and the same person. Again no age effect is seen in the mother, and the proportion of children with mosaicism is about 2 per cent of the Down's Syndrome population (Richards, 1969).

It has been suggested that IQ tends to be higher in people with mosaicism than in those with trisomy 21 (Reisman *et al.*, 1966) and that higher IQ's tend to be found in those with a higher proportion of normal cells (Shipe *et al.*, 1968; Rosecrans, 1968). Recently, however, considerable doubt has been cast on these studies by Gibson (1973) on methodological grounds, since the studies failed to control for, amongst other things, chronological age and the different proliferation rates of normal and abnormal cells. Gibson concludes that there are no grounds for believing that people with mosaicism are likely to have higher IQ's.

Some studies have attempted to relate the physical signs, or stigmata, of Down's Syndrome to IQ, an attempt which is the more difficult since some stigmata may change with age (Gibson and Frank, 1961). Baumeister and Williams (1967) found the studies contradictory, but apart from those where no relationship was found (Shipe *et al.*, 1968) most have reported a positive relationship (Hall, 1964; Gibson and Pozsonyi, quoted by Baumeister and Williams, 1967)—that is the more stigmata the higher the IQ. So, although the findings are inconclusive, it does not appear that a child with fewer physical signs should be expected to be brighter than a child with many signs.

Understandably much effort has gone into attempts to find a physical treatment for Down's Syndrome, but so far with little success. Bardon (1964) reported on a comparison of five experimental and five control subjects given Sicacell treatment and concluded that it was 'completely ineffective'. This was confirmed in a larger study by Black *et al.* (1966). White (1969) lists thyroid and pituitary extracts, glutamic acid, dehydroepiandrosterone, and the Turkel U series as treatments which did not fulfil the high hopes held out for them, and to these she adds Post-Maturation treatment; 44 children received the treatment for periods of up to 11 years, and were compared with 431 untreated children, and no significant differences were found in intelligence scores. Heaton-Ward (1960) reached a similar conclusion concerning the effect of Niamid or of a placebo on 14 pairs of subjects. So far no physical treatment has been shown to have a significant effect on the intelligence of Down's Syndrome subjects.

FERTILITY AND REPRODUCTION

People with Down's Syndrome are very much less likely to have children than are the normal, due perhaps partly to social factors and partly to reduced fertility, but some well-documented cases of reproduction in women with Down's Syndrome have been reported. Finley *et al.* (1968) reported that 15 pregnancies (twins in one case) resulting in 16 infants have been recorded, but the true figures should be 17 pregnancies and 18 infants if the interrupted pregnancies reported by Thompson (1961) and by Tagher and Reisman (1966) are included. Three mothers had had two pregnancies (Hanhart *et al.*, 1961; Thompson, 1961; Tagher and Reisman, 1966). Of the 16 children examined, 8 cytologically, 6 had Down's Syndrome, 2 were retarded—one mildly with an IQ of 67 at the age of 6 (Forssman *et al.*, 1961)—6 were normal, while the stillborn twins did not have Down's Syndrome. So in this small sample just over a third of the children of women with Down's Syndrome also had the condition and just over a third were normal.

Rather little is known of what became of the children, especially of those affected by Down's Syndrome. One such child (Johnston and Jaslow, 1963) was born and brought up in an institution: she was found at the age of 4 years 5 months to have an IQ of 22, compared with her mother's IQ of 44. The mother had been brought up at home, and the author's remark that 'the care and attention bestowed upon the mother tended to give a false impression of mental ability', apparently ignored the possibility that the mother's mental level may have been the true one and that the daughter's may have been depressed by her institutional upbringing. Of the children without Down's

Syndrome, one was severely retarded, unable to stand or talk at the age of 5 (Schlaug, 1957). In the only case where the woman with Down's Syndrome was reported to have been married, to a man of low intelligence, the child at 22 months was reported to be 'completely normal' (Mullins *et al.*, 1960). Four children of other mothers with Down's Syndrome had been fostered and appear to have been happy and well adjusted. One was the mildly retarded boy already mentioned (Forssman *et al.*, 1961); another was adopted at the age of 10 and reported to show normal development and intelligence at that time (Thompson, 1961); another showed essentially normal development by 1 year old (Foxton *et al.*, 1965), while the fourth, a little girl, presumed to have been fathered by her mother's father, was found at the age of 3 years 3 months to have an IQ of 123 (Sawyer, 1949; Sawyer and Shafter, 1957) and later trained as a nurse (Johnston and Jaslow, 1963). Apparently none of these children, either affected or normal, were brought up with their mothers.

No example of a mongol father is known (Penrose, 1963). Stearns *et al.* (1960) studied the reproductive capacity of 21 institutionalized males with Down's Syndrome above the age of 15: sperm counts were grossly subnormal in five, and zero in four subjects while the rest were unable to produce a specimen. So it may be that males with Down's Syndrome have a greatly reduced reproductive capacity.

CHARACTERISTICS

Cognitive

The physical characteristics of people with Down's Syndrome are well known, and a full description of them may be found in Penrose and Smith (1966). Mentally the principal characteristic is subnormality, which is severe in the large majority, although Dunsdon *et al.* (1960) estimated that of 390 children with Down's Syndrome, about 6-7 per cent had IQ's of over 45, and a number of particularly 'high achievers' have been reported (Clarke, 1958; Finley *et al.*, 1965; Carter, 1967; Talkington, 1967; Zellweger *et al.*, 1968). Many studies which have looked at children with Down's Syndrome longitudinally or at succeeding ages from early childhood have found that measured intelligence declines with increasing age from an average of about 70 at 6 months to about 30-40 at 6 to 9 years (Centerwall and Centerwall, 1960; Share *et al.*, 1961; Dameron, 1963; Stedman and Eichorn, 1964; Koch *et al.*, 1963; Shipe and Shotwell, 1965; Dicks-Mireaux, 1966; Cornwell and Birch, 1969). The reason for this decline is unknown; opposing hypotheses are, first, that the baby suffers from a process of deterioration at or soon after birth (Griffiths, reported in Kirman, 1969); and second, that the apparent

decline is a statistical artefact brought about by the construction of infant tests (Bilovsky and Share, 1965). So far this debate is unresolved. The actual levels found vary not only with the age of the children and the tests used but also with whether the children are brought up at home or in institutions. All studies have found the mean IQ's of home-reared children to be superior to those of the institution-reared, although two studies (Lyle, 1960b; Bayley *et al.*, 1966) have found that by giving special attention and stimulation to institution children the gap between them and their home-reared contemporaries was dramatically reduced.

Several investigations have been carried out on the abilities, apart from intelligence, of people with Down's Syndrome. O'Connor and Hermelin (1961) found them to be particularly poor on tests of stereognostic recognition and this was also the finding of Knights *et al.* (1965). O'Connor and Hermelin also found them to be better on tests of visual shape recognition than were other severely retarded children, while Bilovsky and Share (1965) using the ITPA supported this in their finding, that people with Down's Syndrome were especially good at understanding pictures and other visual stimuli and at the same time that they were good at expressing themselves by gesture. Speech has been found to be particularly impaired in Down's Syndrome subjects especially where verbal expression is concerned (Lyle, 1960a; Clausen, 1968; Johnson and Abelson, 1969). These studies have clear implications where the education of Down's Syndrome children is concerned; these children should be taught as far as possible by visual methods, while stereognostic methods such as finger tracing (much favoured by Montessori trained teachers) should not be stressed; while if spoken language is poor these children may be greatly helped by the use of some systematic gestural sign language.

Personality

In the past the personality of people with Down's Syndrome was thought to be characteristic; they were thought to be affectionate, imitative, cheerful, happy and fond of music (Tredgold, 1937). This description was challenged by Rollin (1946) who stressed the variability of personality in people with Down's Syndrome, and by Blacketer-Simmonds (1953) who found them less docile and more mischievous than were other defectives, while he could find no difference in their responsiveness to music. More recently some support has been found for the early stereotype: Silverstein (1964) found patients with Down's Syndrome significantly more often rated by nurses as mannerly, responsible, co-operative, scrupulous, cheerful and gregarious, and higher in general adjustment than were other institutionalized patients. These findings were supported by those of Domino *et al.* (1964) and Domino (1965); the

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first study was carried out by nurses and the second by students who, it was felt, were unlikely to have been influenced by awareness of the stereotype. Ellis and Beechley (1950) found Down's Syndrome children significantly less emotionally disturbed than were other retarded children. Moore *et al.* (1968) and Johnson and Abelson (1969b) using data drawn from the 1966 census of residents in institutions for the retarded in the United States, and comparing data on very large numbers of patients both with and without Down's Syndrome (over 1,000 in the first and over 22,000 in the second study) found those with Down's Syndrome significantly less often rated on maladaptive behaviours such as hyperactivity and aggression, and showing significantly higher levels of social competency in such things as self-feeding and use of toilet and other self-care items. Whether these differences are due to real differences in personality is uncertain. Another suggestion is that the greater tractability of Down's Syndrome subjects as a group may be due at least in part to the comparative rarity of brain damage as shown by epilepsy. Kirman (1951) and Hilliard and Kirman (1965) found that while epilepsy is not unknown in children with Down's Syndrome it is much less frequent than in other severely mentally retarded children, while more recently, an epidemiological study of children in Camberwell showed that 15 per cent of children with Down's Syndrome and 40 per cent of children with other forms of severe mental retardation had a history of epilepsy (Corbett, 1973).

THE OUTLOOK FOR THE FUTURE

The major advances in understanding Down's Syndrome have been, first, identification of the condition by Langdon Down in 1866; second, the discovery of the association between maternal age and the incidence of affected babies (Shuttleworth, 1909); third, identification of the chromosomal abnormality in 1959; the latest step forward is due to the recently developed process of amniocentesis. In this process, amniotic fluid is aspirated from the uterus of the mother at about 14–16 weeks, and this fluid may be cultured and examined for the presence of aberrant chromosomes. If these are found, the situation may be explained to the parents and they may be offered an abortion. Until recently, it did not seem feasible on economic grounds that such a service should be offered to all mothers. However, a four-phased programme of progressive screening, in which first all pregnant women over the age of 40, then those over 35, then over 30 and finally all pregnant women would be offered such a service, has been put forward by Stein *et al.* (1973).

Such a procedure could of course only be offered to the mothers; it could never be obligatory. The final decision either on whether to undergo the diagnostic process or on whether, if an abnormal foetus were detected, to

have an abortion, must rest with the parents. Some would refuse the procedure on religious or ethical grounds. Others might be deterred by fears of possible damage to the foetus, and, since the procedure involves the passing of a needle into the mother's womb, it seems reasonable to fear that it might damage some vulnerable part of the growing foetus. In practice, no damage to the surviving foetus has been encountered (Dr Donald Singer, personal communication). The only damage suffered by the foetus has been by miscarriage. However, the miscarriage rate has not been found to be significantly raised (Stein *et al.*, 1973) while in a study currently in progress (Singer, personal communication) the miscarriage rate for women undergoing amniocentesis is actually lower than for the general population (possibly because of particularly high standards of antenatal care for these women).

It has been proposed that pilot studies of a screening programme of this sort should be set up in this country (MIND 1973) to be followed, if successful, by an extended programme. People with Down's Syndrome comprise about a third of all the severely retarded; such a programme, which might virtually eliminate new cases of the condition, would, in the long run, go far to pay for itself in the economic saving on their lifelong care*. The potential saving in human distress is impossible to estimate.

* It has been estimated that a programme in which every birth in the United Kingdom was screened in this way would cost about £20–25 million per annum. The cost of caring for the whole population of Down's Syndrome people is estimated at £60 million per annum. Office of Health Economics, 1973.

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Populations and Procedures

Originally the intention was to study a population based sample of Down's Syndrome babies; one year's intake of births in the county of Surrey, less the Borough of Croydon, and area 7 of the county of London (then the boroughs of Camberwell and Lewisham). Midwives, Health Visitors, General Practitioners, Consultant Obstetricians, Consultant Paediatricians, Hospital Management Committees and the Boards of Governors of teaching hospitals in the area were asked to refer any Down's Syndrome child born during that period to Dr Valerie Cowie, who carried out neurological and chromosomal studies. It was later thought that a larger sample would provide more comprehensive data, and 19 children (nearly a third of the total) were accepted from the fringes of the prescribed areas. These children were referred by the same paediatricians who referred the children living within the prescribed area, and did not differ significantly in any way from the main group. It had been hoped that the majority of the babies would be referred in time for the psychologist to visit when they were 1.5 months old; in fact about half the babies were referred as early as this and another third by 6 months, while one child was seen for the first time when he was 2 years old.

Fifty-four babies born during the year 1st December 1963 to 30th November 1964 were referred to and were visited by the writer; 25 were boys and 29 girls, 45 were brought up at home, 9 (3 boys and 6 girls) in various foster homes and institutions. One boarded-out child returned to her parents at 15 months, while another, originally brought up at home, was placed in an institution at 1 year. Three boarded-out and 4 home-reared children died during the 5 years of the study. The parents of one home-reared girl refused further contact after the first visit, and the parents of another moved away when she reached 2 years of age. By 4 years 45 children, 39 home-reared and six boarded-out, were still in the study.

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SOCIAL CLASS DISTRIBUTION

The distribution of the home-reared children according to social class (Registrar General (1960) Classification of Occupations) is given in Table 2.1 and the percentages in each social class compared with the percentages found in the census of the London Administrative Area 1961, and for the County of Surrey (1966 Census).

TABLE 2.1*

Social Class Distribution of Families of Down's Syndrome Children: and for London Administrative Area (1961 Census) and for Surrey (1966 Census)†

	Registrar-General's category					Total
	I	II	III non-manual	IV	V	
Down's Syndrome families:						
	No.	4	12	5 III III	12	43
	(%)	9.3	28.0	39.5	9.3	13.9
London Admin. Area:	(%)	4.0	13.0	54.2	11.9	16.9
Surrey:	(%)	9.5	23.9	47.3	14.4	4.9

* Reproduced from Carr, 1970, by courtesy of the editor.

† The social class of two children, each visited only once, is not known.

It is difficult to compare the sample of Down's Syndrome children directly with the population of either London or Surrey, since the children came from both areas. Classes I and II seemed somewhat over-represented in this study but this is probably due to chance; it has been shown (Carr, 1974) that in a larger population sample the social class distribution of Down's Syndrome children is proportionate to that of the population from which they are drawn.

Each Down's Syndrome child living at home was matched for sex, age, and social class with a normal control. This sample of normal babies was obtained with the co-operation of the Statistical Division of Somerset House who, as each Down's Syndrome baby came into the study, supplied names of babies of the requisite sex and social class living in Epsom and Leatherhead (this area, close to the psychologist's home, was chosen to cut down on travelling time).

Three factors on which the two groups, Down's Syndrome children and controls, were not matched were: age of the mother, religion, and size of the family.

Age of the mother

The association between Down's Syndrome in the child and advanced age of the mother at the time of gestation was noticed by Shuttleworth (1909), and subsequent studies have confirmed these findings (Jenkins, 1933; Penrose, 1933, 1934; Øster, 1953). In a study by Penrose (1965) of 2,605 cases of Down's Syndrome, the mean maternal age was 35.1 while the mean maternal age of the same number of control cases was 28.4. In the present study the mean maternal age of the mothers of children with Down's Syndrome is 36.6, while that of the mothers of control children is 28.1. The distribution of ages too is similar in the two studies. Twenty-four per cent and 19 per cent respectively of Down's Syndrome mothers were under 30, compared with just over 60 per cent of controls. Thirty-two per cent and 42 per cent respectively of Down's Syndrome mothers were over 40, compared with 4 per cent and 1 per cent respectively of controls.

In the present study the mothers of the Down's Syndrome children were on average about $8\frac{1}{2}$ years older than were the mothers of the control children. Even had it been possible to match the control group with the Down's Syndrome group for maternal age as well as for other factors it might well not have been desirable to do so, since the children of older mothers may be more subject to a variety of disorders than are children of younger mothers (Tizard and Grad, 1961), and because this would have made them less representative of normal children as a whole. However, the fact that the mothers of Down's Syndrome children were older may have had some bearing on differences between the groups in, for instance, child rearing practices and attitudes, and maternal age will have to be borne in mind when these are being considered.

Religion

Just over a quarter of the mothers of Down's Syndrome children were Roman Catholics, compared with only one mother in the control group (difference significant at 1 per cent level). Again this difference between the groups will have to be considered when differences of attitudes, etc. are being discussed.

Size of families

Since this is a longitudinal study the size of some of the families increased over time, so for the purposes of this discussion family size is taken as at the time of the child's birth. Families of Down's Syndrome children ranged in

size from one to eight children, the controls from one to seven children. As might be expected from the higher age of the mothers, the Down's Syndrome children had more sibs than had the controls: forty-two Down's Syndrome children (home-reared, visited at least twice) had ninety-three sibs (eleven living away from home) while forty-two normal children had fifty-nine sibs. The sibs of the Down's Syndrome children tended to be older; of those living at home, 36 per cent of the sibs of Down's Syndrome children but only 8 per cent of the sibs of controls were over the age of eleven; thirteen families with a Down's Syndrome child had four or more children (including the baby) living at home, compared with six control families. Apart from the higher proportion of older sibs, none of these differences reached significance at the 5 per cent level so family size will not be considered as a relevant variable.

TIMING OF THE VISITS AND SAMPLE SIZE

Visits were planned for 1.5 months, 6 months, 10 months, 15 months, 24 months, 36 months and 48 months. Time limits, of two weeks either way of the exact day (three days either way for 1.5 month visit) were set for visits. It was not always possible to keep to these time limits but, for the Down's Syndrome children, over 80 per cent were seen within the limits at each visit from 6 months to 48 months; at 1.5 months the proportion was 72 per cent, mainly because of delay in telling some mothers of their babies' condition, and hence of permission being given to the psychologist to visit. For the control children, over 90 per cent of all visits except that of 2 years (83 per cent) were paid within the time limits. When the reasons for unpunctuality were examined most were found to be unconnected with the child's condition; changes of address, summer and Christmas holidays and mistakes on the part of the mothers or psychologist account for 63 per cent of all unpunctual visits to Down's Syndrome children; late referrals account for another 25 per cent, while only 12 per cent were caused by illness of the child.

The timing of the visits is not of great importance where the results of tests are being expressed as quotients. The developmental quotient of a 10 month old baby may be usefully compared with that of an 11 month old baby because both age and test-score are taken into account in arriving at the quotient. Timing may become important when test results are expressed in terms of either mental age or of test-score alone. However when the mean mental and motor ages, those calculated on all scores and those calculated only on scores obtained within the time limits, were compared, very small differences were found. Only five were of more than 0.2 of a month (MA) and none of more than 0.6 of a month. In view of these small differences, and in

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order to make use of as much available data as possible, all calculations of mental and motor ages have been carried out on the whole group of subjects.

The number of children seen varied from one age to another, first because more children came into the study as they grew older, and the second because of deaths, moves and one refusal. In addition, a small number of children, five Down's Syndrome and five controls, refused to co-operate in the tests, either the mental scale or motor scale or both, at various ages. Table 2.2 gives the number of home-reared, boarded-out and control children visited, and the number tested at each age.

TABLE 2.2
Numbers Visited and Numbers Tested at Each Age: Home-Reared, Boarded-Out, and Controls

Time visited (months)	Home-reared			Boarded-out			Controls		
	Visited	Tested Mental scale	Tested Motor scale	Visited	Tested Mental scale	Tested Motor scale	Visited	Tested Mental scale	Tested Motor scale
1.5	25*	25	25	4*	4	4	29	29	29
6	34	34	34	8	8	8	35	35	35
10	38	38	38	8	8	8	37	37	37
15	40	38	39	7	7	7	42	41	42
24	40	40	40	7	7	7	42	42	39
36	39	38	38	6	6	6	42	41	42
48	39	36	35	6	6	6	—	—	—

* Children seen first at 1 month and 2 and 2.5 months are included here.

The discrepancies between the numbers of children visited and the numbers tested arose because some children refused the tests on some occasions.

These are as follows:

Down's Syndrome children

15 months: 1 M boy refused the Mental Scale
1 NM boy refused both Scales
36 months: 1 M girl refused both Scales
48 months: 1 NM boy refused the Motor Scale
2 NM girls and 1 M boy refused both Scales.

Controls

15 months: 1 NM girl refused the Motor Scale
24 months: 1 NM girl, 1 M girl and 1 M boy refused the Motor Scale
36 months: 1 NM girl refused the Mental Scale

In the control group, four extra children were accidentally accepted at 1.5 months but were found to be suitable controls for Down's Syndrome children referred later. When a Down's Syndrome child died, if he already had a control child this child was retained in the study, which accounts for the higher number of controls from 15 months onwards.

In the Family Study there were 39 Down's Syndrome children at 15 months and 39 again at 48 months. There were 19 girls and 20 boys. Nineteen families were middle class, 20 working class. Between 15 months and 48 months, two home-reared children died and the family of another moved away, but 3 more children came into the study so that the total number remained the same, as by chance did the numbers of boys and girls and in the social class groups.

Between 15 months and 48 months there had been some changes in the family situations. Three parents of Down's Syndrome children, two fathers and one mother, had died. (Two of these deaths were accidental.) One mother of an illegitimate Down's Syndrome child was living with her parents at 15 months and at 48 months was living with a man whom she shortly afterwards married. One mother in each group was divorced. Altogether 5 Down's Syndrome children and one control were living in one-parent families. Eight mothers of Down's Syndrome children and 17 mothers of controls had more babies during the 5 years of the study; all the babies, 11 in Down's Syndrome and 21 in control families, were normal. One control family moved away when the child was $3\frac{1}{2}$. About one third of the mothers were working at each age; at 15 months all these were working part time, at 48 months one mother of a Down's Syndrome child and two of controls were working full time.

TESTING PROCEDURES

Since the study falls into two parts, the first concerned with the children's development and the second with the effect of the child on the family, the procedures for each will be considered separately.

The developmental study

All the children were visited by appointment in their homes, or in the foster home or institution in which they were being brought up. (One home-reared child moved away to Cornwall at 6 months old and her parents brought her back regularly for testing. She was tested in the psychologist's home.) In the case of the home-reared babies either the mother or sometimes both parents were present (in three cases the father only was present on some occasions). In the case of the boarded-out children, either the foster mother or (for babies in institutions) the nurse who had most to do with the baby was present. The early tests were carried out with the babies in their cots, later they sat on their mother's or nurse's knee at the most suitable table available. For the early tests, efforts were made to ensure that the babies would be awake and

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responsive at the time of testing, and mothers were asked to change an appointment if the one suggested coincided with the baby's usual rest time. All the subjects, Down's Syndrome children and controls, were tested on every occasion by the writer.

The tests used were, first, the Bayley Infant Scales of Mental and Motor Development (Bayley, 1964). These scales were standardized on 1,409 American babies between 1 and 15 months while 'tentative placements' are given for items between 15 and 30 months. An English standardization has been carried out by Francis-Williams and her co-workers on 300 English babies between 1 and 15 months (Francis-Williams and Yule, 1967). The experimental form of the scale was used, which is slightly different from that of the published version (Bayley, 1969). The two scales are administered separately, though some motor behaviour may be observed during testing on the mental scale, and vice versa. From 16 months onwards the full motor scale requires the use of large pieces of equipment which could not easily be carried from place to place so Bayley's shortened form of the motor scale was used.

Means and standard deviations are given for each scale separately at half-monthly intervals from 1 to 15 months and monthly up to 30 months. So in the present survey it has been possible to report DIQ's* based on standard deviations only as far as 24 months. At 36 and 48 months, the scores of the Down's Syndrome children are expressed in terms of mental and motor age.

The second test used was the Stanford Binet form L-M, which was used by Bayley to follow on the experimental form of her scales. Only five Down's Syndrome children gained an IQ on the Stanford Binet at 48 months and one at 36 months, so the scores reported for the Down's Syndrome children are based on the Bayley Scales. At 36 months the controls were given the Stanford Binet form L-M and their scores are reported as IQ's.

The children's scores up to 24 months old expressed as DQ's have been fully reported elsewhere (Carr, 1970) and will be referred to only briefly. We have thought it more useful here to report on the complete range of scores from 1.5 to 48 months, expressed as mental and motor ages.

Family study

The principal aim of the two child rearing surveys described here was to study the effect the very young severely mentally handicapped child has on his

* IQ: Intelligence Quotient. By convention the average IQ is taken to be 100. Between IQ 115 and IQ 85 lie the scores of 68 per cent of the population.

DIQ: Developmental Intelligence Quotient. This is a similar term used by Bayley to refer to the scores obtained on the experimental form of her Mental Scale. In the published version of the Scale this is referred to as the MDI (Mental Development Index).

DMQ: Developmental Motor Quotient. This too is a similar term used by Bayley to refer to scores obtained on the experimental form of the Motor Scale. In the published version of the Scale it is referred to as the PDI (Psychomotor Development Index).

family, and especially to explore what problems arise beyond those which occur with normal children. This was made possible by a comparison of the responses of two groups of mothers, one of Down's Syndrome children and one of normal children. The two surveys in the present study took place when the children were, first, 15 months old and second, 48 months old. The interview schedules were taken from those devised by Drs. John and Elizabeth Newson (for the 15 month survey, from the 'Guided interview schedule for mothers of children aged one year': for the 48 month survey, from the 'Guided interview schedule for mothers of cerebral palsy children', Hewett, 1970) with some alterations to adapt the schedules for use with mothers of mentally handicapped children.

The two schedules used in the present study are shown in Appendices II and III. Interviews were carried out after the testing of the child was completed. The order of questions in the schedules was kept to loosely, but if a mother spontaneously began to talk on a subject due to be discussed later her comments would be recorded in the appropriate place. A tape recorder was not used but the interviews were recorded in writing by the interviewer, who checked the appropriate categories on the schedules and wrote down verbatim as much as possible of the mother's replies. As Hewett (1970) found, most of the interviews were about $1\frac{1}{2}$ to 2 hours long but some took as little as three-quarters of an hour and some 3 hours or more.

The interviews with mothers of Down's Syndrome and control children were carried out in the same way though there were some questions which were not appropriate to and were not asked of the mothers of the control children. All the interviews were carried out by the writer.

In considering the results in the family study it is important to bear in mind that almost all the evidence is derived from mothers' reports, and not from direct observation. How far then may we believe the reports to be true? How far can it be accepted that what a mother says she does is what she actually does? It is quite possible, for a number of reasons, that not all the reports are strictly true. A mother may not remember accurately the facts that she is recounting. She may, consciously or unconsciously, wish to present herself in a good light to the interviewer. She may want to present herself in a good light to herself*. To accept at face value all that we are told, even if there is no obvious material advantage to be gained by prevarication, would be naive.

Ideally another study should be carried out parallel with the interviews, in which the mother would be observed interacting with her child, so that her actual behaviour could be compared with her reported behaviour. One study along these lines is that by Douglas *et al.* (1968) in which a child's

* What constitutes a good light may vary from one person to another; for instance, the behaviour which to one mother suggests unkindness may be thought of by another as showing commendable firmness.

activities and interaction with his mother during a four-hour morning session were recorded by one interviewer, and the mother's report of these activities and interactions given to another interviewer during the same afternoon. The two records were very similar, so in this case the mother's report of what had happened could be accepted as true. Douglas' study differed from the present one in two ways: one, it was the amount of interaction that was recorded, not its quality—the amount of time spent in kissing and in smacking, for example, seemed to be indistinguishable; and two, the events recalled were very recent, having taken place not more than six or seven hours earlier, whereas in our studies some events (breast feeding, for instance) may have occurred several months earlier. However, Douglas' study suggests that some confidence may be placed in mothers' reports.

No such systematic observations have been carried out here. By the time the enquiries were complete the writer had visited the homes and tested the children on up to seven occasions and so had got to know the families quite well. On the whole the impression gained was that the mothers' reports of what they did coincided reasonably well with what they were observed to do, at any rate in those aspects of their behaviour that could be observed. This was not always the case; one mother, asked how she punished her 15 month old when he was naughty, said, 'I just tap his hand and say, "Naughty"', when she had been observed, during that interview, shouting and slapping at the baby. But such gross discrepancies between observed and reported behaviour were unusual. In the discussion of this study, then, it is thought that a cautious confidence may be placed in the mothers' reports of their own and their babies' behaviour. Nevertheless wherever the reader encounters statements beginning 'so many mothers do this', or 'so many babies do that', he should understand that these may always be prefixed with, 'the mothers say that . . .'; and may take them with as large a pinch of scientific salt as he deems appropriate.

Section I

The Developmental Study

3

Results From Developmental Testing

HOME-REARED AND BOARDED-OUT DOWN'S SYNDROME CHILDREN AND CONTROLS

Mental scale

A graph of mean DIQs for home-reared and boarded-out Down's Syndrome children, and for controls, from 1.5 months to 24 months is given in *Figure 1*.

TABLE 3.1
Mean Mental Ages,* Home-Reared and Boarded-Out Down's Syndrome Children
(in months)

		<i>Home-reared</i>	<i>Boarded-out</i>
1.5 months	Mean	1.05	1.44
	S.D.	0.46	1.14
6 months	Mean	4.76	4.75
	S.D.	0.56	0.41
10 months	Mean	6.67	5.60
	S.D.	1.03	1.04
15 months	Mean	9.26	7.49
	S.D.	1.37	1.68
24 months	Mean	13.44	10.71
	S.D.	2.36	2.40
36 months	Mean	17.25	13.38
	S.D.	3.48	3.68
48 months	Mean	21.94	16.92
	S.D.	5.28	4.70

* Mean mental ages are not given for the controls since these were close to their chronological ages.

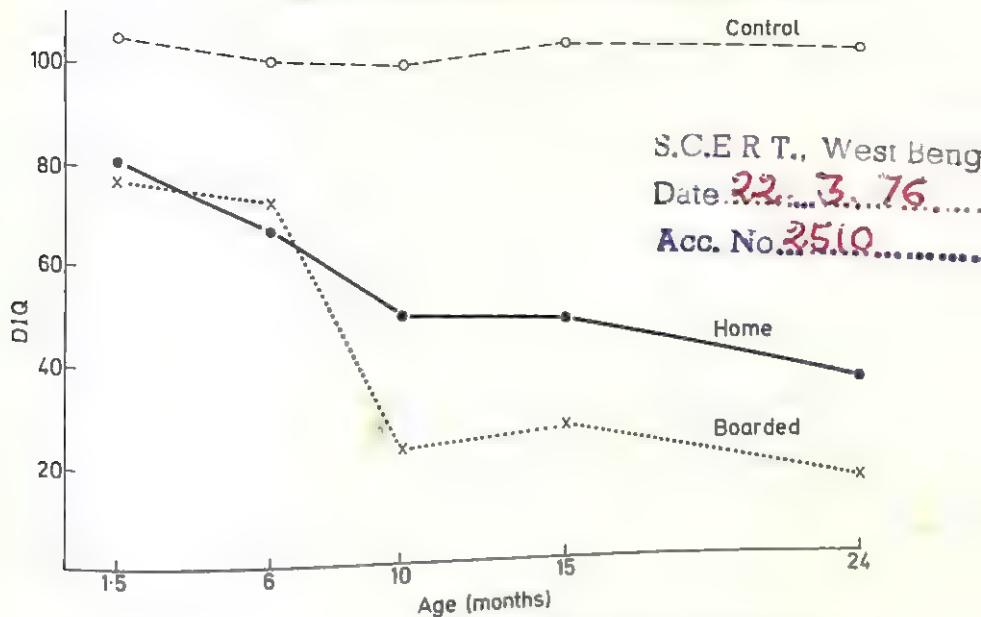


Figure 1. DIQs, home-reared and boarded-out Down's Syndrome children, and controls, 1.5 to 24 months (reproduced from Carr, 1970, by courtesy of the editor)

Table 3.1 shows the mean mental ages for home-reared and boarded-out Down's Syndrome children from 1.5 months to 48 months.

Figure 2 shows the mean mental ages to 4 years old for the home-reared and boarded-out Down's Syndrome children in graph form. At 1.5 months the mean DIQ in both Down's Syndrome groups was well below that of the control group, the difference between Down's Syndrome and control groups being significant at less than the 0.01 level (Mann-Whitney U test, $U = 83$). In the home-reared group the mean DIQs dropped fairly sharply to 10 months old, flattened out to 15 months, and dropped more gradually to 2 years. In the boarded-out group the drop was much steeper to 10 months, followed by a rise to 15 months and a falling away to 2 years proportional to that found in the home-reared group. That the intelligence of young Down's Syndrome children declines with increasing age has been shown in several studies (Centerwall and Centerwall, 1960; Share *et al.*, 1961; Dameron, 1963; Koch *et al.*, 1963; Shotwell and Shipe, 1964; Stedman and Eichorn, 1964; Shipe and Shotwell, 1965; Bayley *et al.*, 1966; Dicks-Mireaux, 1966). The present study suggests that this decline takes place very early. Nevertheless at 1.5 months, although the mean score of the Down's Syndrome children was significantly below that of the controls, no fewer than 17 of the 25 tested (68 per cent) gained a score of 80

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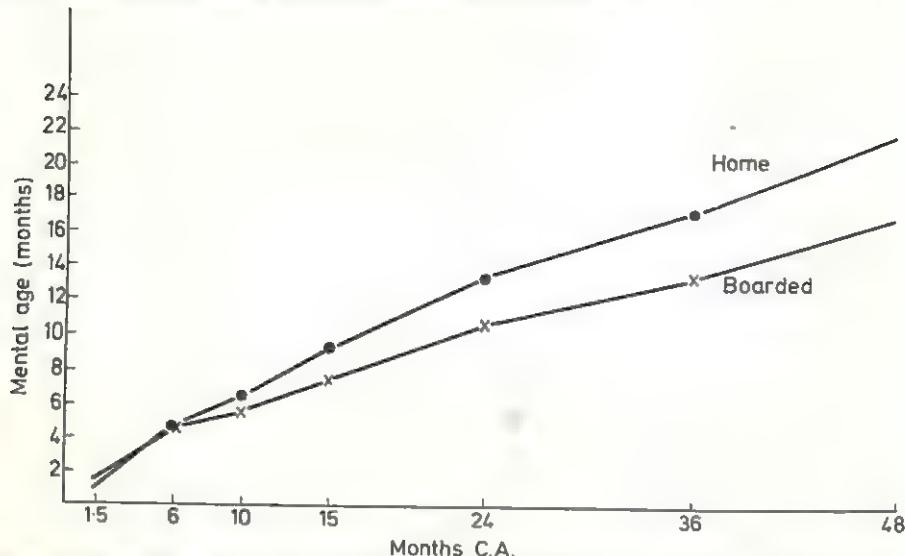


Figure 2. Mental ages, home-reared and boarded-out Down's Syndrome children, 1.5 to 48 months

or more; as did 34 per cent at 6 months and 4 per cent at 10 months. On the basis of test score alone these children would not then have been regarded as likely to be retarded in the future. (Many predictive studies of retarded children have used 70-80 as the cut-off point—Drillien, 1961; Werner *et al.*, 1968.) Where prediction was concerned, one would have had greater success if the entire group of Down's Syndrome children had been rated as severely subnormal (as would have been reasonable in view of the diagnosis) than if predictions had been made on the basis of infant test scores.

The halt in the downward trend of the Down's Syndrome children's DIQs between 10 and 15 months is interesting, especially as it is paralleled by a slight rise of +5.2 DIQ points in the mean scores of the control children (though this rise is not significant). It should be noted that this slight improvement in the mean scores of all the children does not suggest that the test items were relatively easier at 15 months than they were at 6 or 10 months, since the Down's Syndrome children were attempting and passing quite different groups of items from those undertaken by the controls. (For example, the control children were performing fairly complicated manipulative tasks with pegs, bricks and form boards, while the Down's Syndrome children were concerned with much simpler tasks such as grasping bricks and lifting a cup. The control children used a good many speech sounds and some words, and these were seldom heard at this age from the Down's Syndrome children.) One factor contributing to the less rapid decline of the Down's Syndrome children's mean DIQs at 15 months was large increases

of some individual scores at this age. The scores for each Down's Syndrome child were examined at each age from 1.5 to 24 months; this showed that, while small gains and losses of score occurred between every adjacent pair of ages, large variations (of 20 or more DIQ points) were in the downward direction only in every case except between 10 and 15 months. At this time the scores of 5 children (4 home-reared and 1 boarded-out) rose by 20 or more points, while the scores of 4 children (3 home-reared and 1 boarded-out) dropped by 20 or more points. Apparently some large increases in scores between 10 and 15 months counteracted the general tendency to lower scores.

Overall the Down's Syndrome children showed more of the larger DIQ variations than did the controls. Forty-nine per cent of the variations in the Down's Syndrome children's DIQs were of over 30 points, compared with 17 per cent of the variations of the control children; 27 per cent in the Down's Syndrome group were over 40 points (the largest being 81) compared with none of the controls.

Varying test conditions might have been expected to account for most of the test variations—that is, if a child behaved well in one test, and behaved badly or seemed tired in the second, it might be expected that his score on the second test would be lower than his score on the first. A rating of the adequacy of the test was made on every child each time he was tested as part of the Bayley Infant Behaviour Profile and these ratings were examined to see whether a large decrease in DIQ was accompanied by a lower rating of test adequacy than that given for the previous test, and vice versa. In only 23 per cent of the cases were the ratings in the expected direction—i.e., lower ratings where there were score losses, and vice versa. So in over three-quarters of the cases it did not seem that varying test conditions could account for the large variations in scores. This suggests that the pattern of development of Down's Syndrome children may be not only slower but different from that of normal children. It seemed to the writer that the Down's Syndrome infant often stayed much longer at one stage of development, that the 'plateaux' of his achievements were more extended. If then he were tested towards the end of a plateau, when his progress had been relatively stationary for a long time, his DIQ would seem to have fallen, whereas if he were later tested when he had just made the step up from the plateau his DIQ would appear to have gone up. This view of the Down's Syndrome child's rate of development is consistent with that often expressed by the mothers; it was a commonplace for a mother to remark, 'You think he's never going to do a thing, and then suddenly he does it, all in a rush.' There is in the present study no satisfactory evidence either to support or refute such a view of the development of children with Down's Syndrome, because of the wide intervals between tests; but it would be interesting if another study with tests given at, perhaps, fortnightly intervals, could either

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substantiate or disprove with test scores the subjective impression of prolonged plateaux in the development of Down's Syndrome children. Such a study might also show why these variations in development were so much more prominent during the early months: this may have been related to the fact that normal development, against which that of the Down's Syndrome child is measured, is so rapid at this time.

COMPARISON BETWEEN HOME-REARED AND BOARDED-OUT DOWN'S SYNDROME CHILDREN

In the Down's Syndrome group, comparison of the curves of mental age scores of home-reared and boarded-out children shows a significant difference in the slopes of the lines, with the curve of the boarded-out children's scores more irregular in shape than that of the home-reared children, showing relatively slower increases in mental age between 6 and 10 months, and between 2 and 3 years. One may speculate that between 6 and 10 months the boarded-out children were beginning to feel the effects of their different environment, although normal children may respond to institutionalization with developmental retardation much earlier (Rutter, 1972, page 30). Between 2 and 3 the difference may have been largely due to differences in verbal development; at 3 years the home-reared children passed almost twice as many verbal items for the first time as did the boarded-out. (Home-reared children passed an average of 3.9 new verbal items, boarded-out an average of 2.)

In addition to the difference in the slopes of the regression lines, the mean scores of the boarded-out children were below those of the home-reared after 6 months and the difference between these two curves of scores is significant at the 1 per cent level. This difference, with the scores of the boarded-out children significantly below those of the home-reared, supports the findings from other studies, that children with Down's Syndrome brought up at home make better developmental progress than those brought up in an institution. (Centerwall and Centerwall, 1960; Stedman and Eichorn, 1964; Shipe and Shotwell, 1965.) It has been suggested (Birch and Belmont, 1961) that this difference is due not to differences in the rearing environment but to selective factors determining those children to be fostered—that these were 'initially significantly more defective than were the home-reared infants'. This suggests that the parents, never having seen a Down's Syndrome baby before, can recognize that one baby is more severely handicapped than another and dispatch him to an institution—and in the neonatal period too. The alternative hypothesis, that the difference in degree of retardation between the two groups is due to the difference in their environments, is better supported by the available evidence. Studies by

Tizard (1960), Stedman and Eichorn (1964), and Bayley *et al.* (1966) show not only the customary difference between the scores of home-reared and institutionalized children, but also that when efforts are made to improve the environment the institutionalized children may catch up to a large extent with the home-reared. Tizard's well known study showed that children moved from a hospital to a small children's home (Brooklands) improved significantly in verbal ability. Stedman and Eichorn, and Bayley *et al.*, studied the same two groups of 10 home-reared and 10 institutionalized Down's Syndrome children. At an average age of 28 months the mean DIQs were 52.1 and 37.3 respectively, and at an average of 61 months mean ratio IQs were 40.4 and 29.8 respectively (both differences being significant at or below the 0.01 level). After this second comparative test, and the observation that the most striking deficit in the hospital group was in language development, 'an intensive ward programme designed to increase the receptive and expressive language abilities of the hospital children was begun' (Bayley *et al.*, 1966). Three hours a day were spent in group instruction, using books, puzzles, finger-plays, etc., two hours in large muscle activities, and each child received an average of 15 minutes daily instruction on a one to one basis. Staff were encouraged to talk to and encourage talking from the children, and 'stress has been placed on always expecting . . . a little bit more from the child than the adult anticipates he will be able to give'. At an average of 13 months later, the mean ratio IQ of the hospital group was 36.3 and that of the home group 42.5 and this difference was not significant.

From the present study too there is some evidence that goes against Birch and Belmont's suggestion that the more damaged children are those selected for institutionalization*.

The early scores of the two groups, at 1.5 months and at 6 months, are closely similar, suggesting that these boarded-out children started with 'normal' Down's Syndrome abilities. That their scores were later consistently and significantly below those of the home-reared suggests that their development was adversely affected by their environment. This is especially interesting since the environment for these children was apparently quite varied; four children were placed in small foster homes, in which there were not more than three other foster children; five were sent to larger institutions. Contrary to expectations the children in foster homes have not done noticeably better than those in institutions. Lyle (1960b) showed that Down's Syndrome children made relatively less progress in speech when they were moved to a more stimulating environment than did other imbecile children. In the present study numbers are too small to permit a comparison of the relative merits for Down's Syndrome children of institution and foster

* In fact social reasons seem to have been predominant in deciding which children should be boarded-out. Three children were illegitimate, one had been the cause of a forced marriage and his parents separated after his birth, and one mother deserted the family after the child's birth.

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homes, and a larger scale study of this subject would be valuable. There can be little doubt however that a child with Down's Syndrome has the best chance of developing his potential if he is brought up in his own home by his own family.

Motor scale

Mean motor ages for the home-reared and boarded-out Down's Syndrome children from 1.5 months to 48 months are shown in Table 3.2.

Motor ages are given in the Bayley norms up to 30 months, point score = 57.0. At 48 months some Down's Syndrome children exceeded that point score, and so could not be given motor ages. Therefore at 48 months means have been calculated on the raw (point) scores and the means converted roughly into motor ages.

Figure 3 shows the mean motor ages for the same groups in graph form. As on the mental scale the mean scores for the home-reared children are significantly above those for the boarded-out. Again there is a significant difference in the slopes of the regression lines; the curve of scores for the home-reared rises more steeply than that of the boarded-out, especially between 2 and 3 years. Rather surprisingly this does not seem to be due to differences in ability to walk (two-thirds of the children in each group learnt to walk by 3 years old). At 3 years however there were differences between the groups in more advanced motor skills—proportionately at least twice as many of the home-reared children were able to pass items concerned with

TABLE 3.2
Mean Motor Ages, Home-Reared and Boarded-Out Down's Syndrome Children
(in months)

		<i>Home-reared</i>	<i>Boarded-out</i>
1.5 months	Mean	1.34	1.76
	S.D.	0.40	1.07
6 months	Mean	4.54	4.31
	S.D.	0.64	0.58
10 months	Mean	6.11	5.19
	S.D.	0.79	0.91
15 months	Mean	8.35	6.77
	S.D.	1.44	1.59
24 months	Mean	11.32	9.38
	S.D.	1.95	1.99
36 months	Mean	18.42	13.77
	S.D.	5.41	4.19
48 months	Mean	ca. 24	ca. 17
Raw score	Mean	54.67	51.17
Raw score	S.D.	5.48	5.53

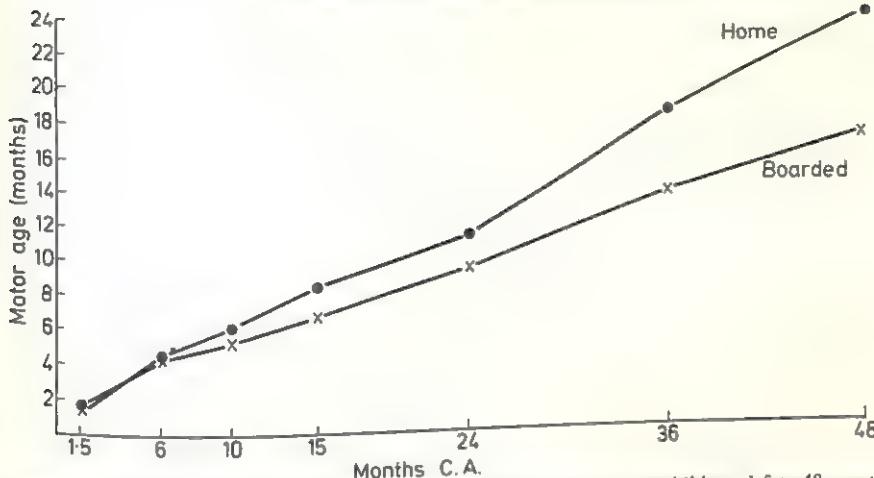


Figure 3. Motor ages, home-reared and boarded-out Down's Syndrome children, 1.5 to 48 months variations in walking (sideways, along a line, etc.) and in balance and agility. The greater sophistication of motor ability in the home-reared children at this age may have contributed largely to the difference between the slopes of the two lines.

BOYS AND GIRLS

Mental scale

In the control group no significant differences were found between the mean scores of boys and girls on either scale. In the Down's Syndrome group the mean mental age scores of the girls were consistently higher than were those of the boys (the difference not quite significant at the 5 per cent level) (Figure 4).

Few studies in the literature have compared the intellectual levels of male and female Down's Syndrome subjects, but of those that have all found females to be the higher (Brousseau and Brainerd, 1928; Wallin, 1944; Sternlicht and Wanderer, 1962). In the present study there was no significant difference between the sexes in the size of standard deviations (Table 3.3); however inspection of the top and bottom quarter of the scores at each age showed that there were rather more high scoring girls (overall total, girls = 49, boys = 33) and nearly twice as many low scoring boys (overall total, boys = 48, girls = 26). So it may be that the difference in mean scores between the sexes is due mainly to the higher proportion of very severely retarded boys in this study.

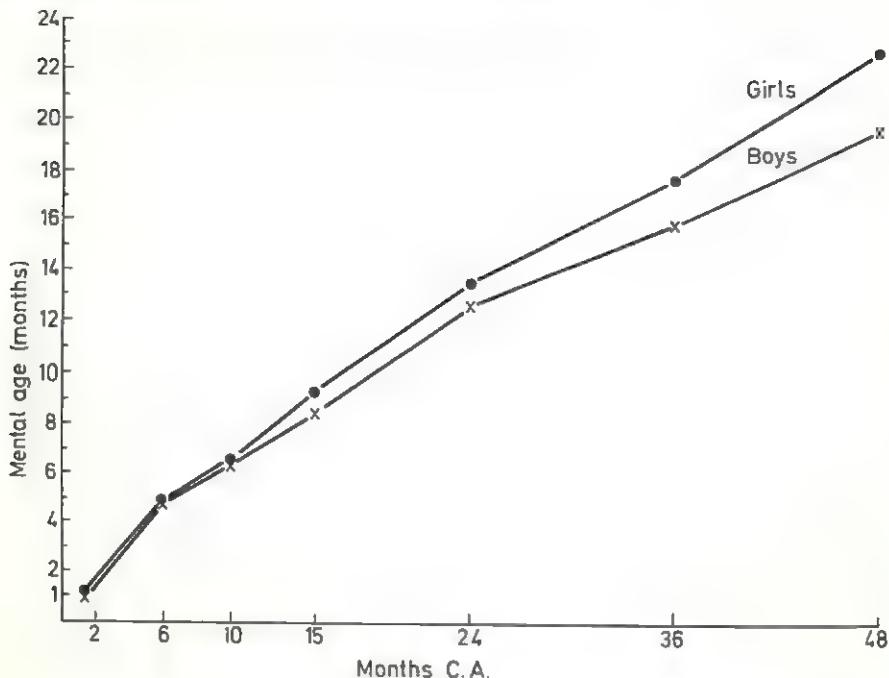


Figure 4. Mental ages, boys and girls, Down's Syndrome children, 1.5 to 48 months

In addition to the difference in the position there was also a significant difference in the slope of the regression lines of the scores of the sexes, probably due to the steeper rise of the girls' scores between 24 and 48 months. Here again differences in verbal ability may be important. At 3 years the girls passed more verbal items for the first time than did the boys and at 4 years passed twice as many (girls' average 8.2, boys' average 4.1). In normal children little girls are commonly found to be more advanced in verbal ability than little boys (McCarthy, 1954; Moore, 1967; Neligan and Prudham, 1969), though boys have been found to surpass the girls at later ages (Templin, 1957; Moore, 1967). In Moore's study the girls were significantly higher on the speech quotient at 18 months, 'during the period of acquisition of language', but not at 3 years or after. It is interesting that the Down's Syndrome subjects in this study showed the same sex difference, at an average mental age of 22 months, when they were certainly acquiring language (and still had a long way to go in doing so). It would be interesting to know whether the second part of the pattern in normal children, the later superiority of the boys, will be repeated in the Down's Syndrome children, but that is outside the scope of the present study.

TABLE 3.3
Mean Mental Ages, Boys and Girls: Down's Syndrome Children (in months)

Months		Boys	Girls
1.5	Mean	1.0	1.2
	S.D.	0.54	0.67
6	Mean	4.8	4.7
	S.D.	0.66	0.40
10	Mean	6.4	6.6
	S.D.	1.09	1.12
15	Mean	8.5	9.3
	S.D.	1.67	1.38
24	Mean	12.6	13.5
	S.D.	2.75	2.25
36	Mean	15.9	17.6
	S.D.	3.67	3.64
48	Mean	19.7	22.7
	S.D.	5.06	5.49

Motor scale

On the motor scale the difference in position of the curves of the boys' and girls' scores was not significant, so although the girls' scores were consistently above the boys' the difference was not a significant one. However there was a significant difference in the slope of the regression lines which again seems likely to be due to the steeper rise in the girls' scores after 24 months. Most of the items in which the girls were at 36 and 48 months particularly advanced (stands on one foot alone, walks backwards or on tiptoe, jumps etc.) depend to a large extent on the child's co-operativeness and willingness to carry out the examiner's instructions, while this is not true of the one item in which the boys were more advanced (sits down). So while the difference in the shapes of the curves of the motor scores may be due in part to the girls' more sophisticated ability at 36 and 48 months, it may also be due in part to their better co-operativeness and comprehension of verbal instructions.

SOCIAL CLASS

Mental scale

In the control group, mean scores (DIQs) of the non-manual children were consistently above those of the manual children, the difference between the

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two curves of scores being significant at the 0.1 per cent level. Testing at individual age levels, a difference significant at the 1 per cent level was found at 2 years but not at 15 months or before. This is in accordance with Hindley's (1961) finding that a significant difference appeared between the social classes at 3 years but not at 18 months.

In the Down's Syndrome group, the scores of the non-manual children were slightly below those of the manual group but the difference was not significant.

TABLE 3.4
Correlations Between Mental Ages, 1.5 to 48 Months (Down's Syndrome);
1.5 to 36 Months (Controls)

Time of test (months)	Down's Syndrome children: mental age (months)					
	1.5	6	10	15	24	36
1.5 N	—	—	—	—	—	—
6	0.23	—	—	—	—	—
N	29	—	—	—	—	—
10	0.35	0.53xxx*	—	—	—	—
N	28	41	—	—	—	—
15	0.22	0.43xx	0.76xxx	—	—	—
N	27	40	44	—	—	—
24	0.28	0.29	0.62xxx	0.80xxx	—	—
N	25	38	43	43	—	—
36	0.04	0.29	0.64xxx	0.78xxx	0.87xxx	—
N	23	36	40	41	44	—
48	0.08	0.20	0.64xxx	0.72xxx	0.83xxx	0.92xxx
N	21	32	36	37	40	39
Controls: mental age (months)						
	1.5	6	10	15	24	—
	—	—	—	—	—	—
1.5 N	—	—	—	—	—	—
6	0.65xxx	—	—	—	—	—
N	29	—	—	—	—	—
10	0.37	0.66xxx	—	—	—	—
N	27	33	—	—	—	—
15	0.22	0.62xxx	0.66xxx	—	—	—
N	29	35	37	—	—	—
24	0.40x	0.43xx	0.38x	0.54xxx	—	—
N	29	35	37	41	—	—
36	0.34	0.31	0.50xx	0.52xxx	0.77xxx	—
N	28	34	36	40	41	—

* Levels of significance are indicated by: x = 5% level
xx = 1% level.
xxx = 0.1% level.

Motor scale

On the motor scale a similar pattern of scores was found: in the Down's Syndrome group mean scores of the manual children tended to be above those of the non-manual, while the reverse was true for the controls. In neither case were the differences between the social class groups significant.

CORRELATIONS BETWEEN SCORES AT DIFFERENT AGES

Mental scale

Correlations between mental ages at each age level for Down's Syndrome children and controls are given in Table 3.4.

For the Down's Syndrome children none of the correlations with the 1.5 month test was significant, but most after that time were significant, and from 10 months onwards all coefficients were significant at less than the 0.1 per cent level. For the controls the picture was more varied, with a general tendency for correlations to be highest between adjacent age levels. In both groups correlations became higher with increasing age: after 10 months all the Down's Syndrome children's coefficients were over 0.7, and those of the controls over 0.5.

It was thought that the prediction of future intellectual status would be more accurate for the Down's Syndrome than for the control group. However, overall there was no significant difference between the two groups in the size of the correlations (Wilcoxon Matched-Pairs Signed Ranks test: $N = 14$, $T = 45$; not significant at the 5 per cent level). The correlations for the controls tended to be higher for the early tests, and those for the Down's Syndrome children for the later tests, from about 10 months onwards. This agrees with the findings of Knobloch and Pasamanick (1960) that infant tests are more efficient predictors of the later ability of retarded than of normal subjects, since they compared results obtained on tests at 9 months with those at 3 years.

Although the correlations on the scores of the Down's Syndrome children are higher than those reported for normal children (Bayley, 1949; Moore, 1967) they are not high enough to allow useful prediction to be made for individual children. The possibility of useful prediction for individual Down's Syndrome children in the present study was further explored by selecting those whose scores were comparatively high and those whose scores were comparatively low from 10 months onwards (roughly the top and bottom 25 per cent) to see whether they retained a similar position at 48 months. The results are shown in Tables 3.5 and 3.6.

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TABLE 3.5
Numbers of High Scorers at 10, 15, 24 and 36 Months Who Scored Highly at 4 Years

High scorers at:	N	MA	DIQ	No. of high scorers, MA 24 months + at 4 years
10 months	13	7 months +	61 +	4
15 months	12	10 months +	58 +	6
24 months	12	14 months +	43 +	6
36 months	13	18 months +	-	9

TABLE 3.6
Numbers of Low Scorers at 10, 15, 24 and 36 Months Who Scored Poorly at 4 Years

Low scorers at:	N	MA	DIQ	No. of low scorers, MA 17 months - at 4 years
10 months	10	5.6 months -	32 -	5
15 months	10	7.8 months -	35 -	5
24 months	10	11.7 months -	24 -	6
36 months	10	15.0 months -	-	8

Between 10 and 24 months no more than half of the high scorers were also high scorers at 4 years. At 36 months the proportion rose to nearly three-quarters (the correlation between the mental age scores at these ages was 0.92). The situation was similar in regard to the low scorers. So it is clear that detailed prediction of future intellectual status, even for these severely retarded children, cannot be made with any confidence at least up to the age of 2. This agrees with the findings of Fishler *et al.* (1965) that 'the scores of early DQ's of mongols at one and two years did not offer validity in predicting future IQ'. There was however little overlap between the children in the two extreme groups: so that although if between 10 and 36 months a child scores at a high level it is not possible to predict that he will continue at that level, it is unlikely that he will later score at the lowest level.

Motor scale

Correlations between motor ages at each age level for the Down's Syndrome group are given in Table 3.7.

As with the mental ages, none of the correlations between motor scores at 1.5 months and at later ages was significant, but all after that time were significant and from 10 months onwards all were significant at less than the 0.1 per cent level.

TABLE 3.7

Correlations Between Motor Ages, 1.5 to 48 Months, for Down's Syndrome Children

Age (months)	1.5	6	10	15	24	36
1.5	—	—	—			
N	—	—	—			
6	0.23	—	—			
N	29					
10	0.13	0.63	—			
N	28	41				
15	0.05	0.46	0.69xxx			
N	27	40	44			
24	0.17	0.48xx*	0.57xxx	0.79xxx		
N	25	38	43	43		
36	0.09	0.36x	0.63xxx	0.79xxx	0.77xxx	
N	23	36	40	41	44	
48	0.33	0.46xx	0.71xxx	0.78xxx	0.68xxx	0.80xxx
N	21	32	36	37	40	39

* Levels of significance: $x = 5\%$ level
 $xx = 1\%$ level.
 $xxx = 0.1\%$ level.

COMPARISON OF THE MENTAL AND MOTOR SCALES

The correlations between the two scales for Down's Syndrome children are given in Table 3.8.

Figure 5 shows the comparison between mean mental and motor ages for Down's Syndrome children from 1.5 to 48 months in graph form.

The correlations between scores on the two scales are all significant at

TABLE 3.8
Correlations Between Scores on the Mental and Motor Scales

Down's Syndrome children (Mental and motor ages)							
1.5 months 0.57xxx*	N 30	6 months 0.61xxx	N 42	10 months 0.76xxx	N 46	15 months 0.80xxx	N 45
24 months 0.73xxx	N 47	36 months 0.77xxx	N 44	48 months 0.76xxx	N 40		
Controls (DIQ's and DMQ's)							
1.5 months 0.63xxx	N 29	6 months 0.71xxx	N 35	10 months 0.62xxx	N 37		
15 months 0.48xxx	N 41	24 months 0.60xxx	N 39				

* Level of significance xxx = 0.1%.

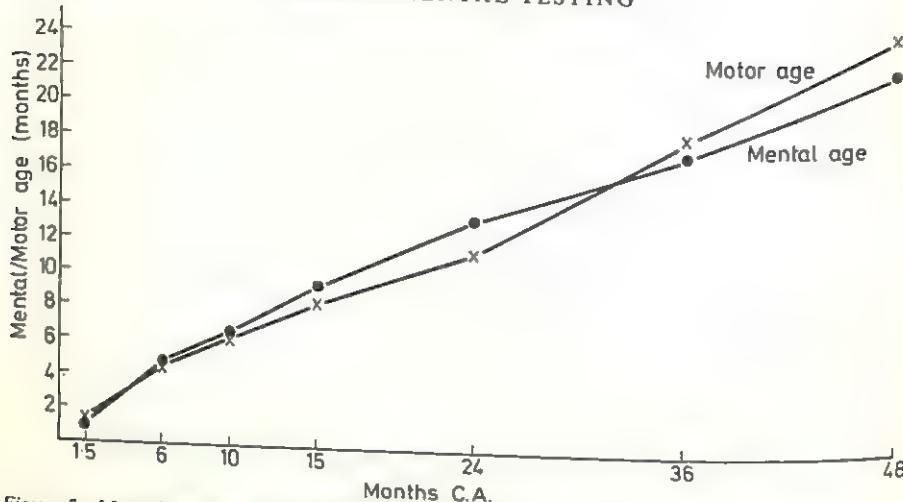


Figure 5. Mental and motor ages, home-reared Down's Syndrome children, 1.5 to 48 months

less than the 0.1 per cent level, similar to the results found on normal children by Bayley (1969) and rather higher than those found by Francis-Williams and Yule (1967). For the Down's Syndrome children mean motor scale scores were generally lower than mean mental scale scores, up to the point (36 months) when the majority learned to walk, when mean motor scores became the higher.

Normative data

Some normative data for the Down's Syndrome children, on mental and on motor scale items, are presented in Tables 3.9 and 3.10. Although the study was not designed to collect normative data and, as the tests were spaced far apart and irregularly, was not very suitable for that purpose it is possible to give some data in a rather limited way; for instance it is possible to say that none of the children was capable of a social smile at 1.5 months, but that all were by 6 months. In order to include as much data as possible, and because in general the scores for the home-reared and boarded-out children fell within the same range (exceptions to this are given at the foot of the tables) the data for the two groups have been combined.

Walking

In addition to the data on the ages at which the children were tested and seen to be walking, data are available on reported ages of walking; at 4 years old

the mothers and nurses were asked when the child had first walked alone (defined as taking at least 3 steps without support).

The data are given in Table 3.11.

TABLE 3.9
Cumulative Percentages of Down's Syndrome Children Passing Mental Scale Items at Different Ages*

Bayley No.	Item	1.5	6	10	Age (months)				not by 48	No.
					15	24	36	48		
18	Social smile (1.5)†	—	100							29
47	Turns head to bell (3.8)	64	100							42
48	Turns head to rattle (3.9)	52	100							42
66	Bangs in play (5.5)	13	72	96	98	100				45
69	Transfers object hand to (5.4)		9	51	94	98	100			45
80	Pulls string adaptively (7.1)		2	18	82	93	100			45
<i>Vocalizations</i>				10	15	24	36	48	not by 48	No.
79	Vocalizes 4 different syllables (7.0)		24	64	96	98			2	45
85	Says 'da-da' or equivalent (7.9)		25	69	96	98			2	48
113	Says two words (14.2)				14	57	77	23	23	44
127	Uses words to make wants known (18.8)				5	23	41	59	59	44
136	Joins two words (20.6)						5	21	79	43

* The ages at which the boarded-out children passed the items fell within the range of the home-reared, except for item 66, in which the last two children to pass, at 24 and 36 months, were from the boarded-out group.

† Figures in brackets are those given by Bayley (1969) as the average age of passing for normal children.

TABLE 3.10
Cumulative Percentages of Down's Syndrome Children Passing Motor Scale Items at Different Ages*

Bayley No.	Item	1.5	6	10	Ages (months)				not by 48	No.
					15	24	36	48		
14	Head steady (2.5)	—	86	100						29
19	Head balanced (4.4)		38	89	98					47
20	Effort to sit (4.8)		25	88	96	98	100			45
29	Sits steadily (6.6)			19	72	98	100			47
33	Crawls (7.1)				4	37	93	98	100	46
41	Fine prehension (8.9)					22	40	82	91	9
42	Walks with help (9.7)						60	84	93	7
44	Pat-a-Cake (9.6)						40	71	96	4
46	Walks alone (11.7)						30	82	93	48

* The ages at which the boarded-out children passed the items fell within the range of the home-reared except for items 19 and 20, in which the last child and the last three children respectively to pass were from the boarded-out group.

TABLE 3.11
Mean Reported Ages of First Walking (in months)

Down's Syndrome Children	N	Mean age	Range
Home-reared	35	28.5	14-48
Boarded-out	6	35.2	20-48
Boys	20	29.9	14-48
Girls	21	29.0	18-47
<i>Controls</i>	38	14.4	7-24
Boys	18	14.5	9-20
Girls	20	14.3	7-24

Three boys, 2 home-reared and 1 boarded-out, were not walking when they were tested at the age of 4. These have been assigned an arbitrary walking age of 48 months. This assumes that these boys walked within a month of the test and this may underestimate their true walking age: but this is less misleading than omitting them from the table altogether. The home-reared children were reported as walking at an average of 7 months earlier than the boarded-out, though there was little difference between the boys and girls.

Six mothers definitely underestimated the age at which their children walked; that is, the children were tested and found to be unable to walk at an age older than that at which their mothers reported that they were able to walk. No mother overestimated the child's walking age.

In the Down's Syndrome group, the data from the present study are similar to those in other studies in finding that most children sat up by 15 months, crawled by 2 years, and walked by 3 years. The data on the boarded-out children are in agreement with the findings of others (Centerwall and Centerwall, 1960; Kugel and Reque, 1961; Donoghue *et al.*, 1970) that institution-reared children tend to walk later than do those reared at home. It seems important to know, in studies of the motor abilities of retarded children, first whether the children were home- or institution-reared, and secondly whether the data were from direct observation or from the reports of mothers; if they are the latter, the mean ages are likely to be, if anything, optimistic.

SUMMARY AND DISCUSSION

So from this part of the study the major findings are: that the scores of children with Down's Syndrome were below those of the controls at 6 weeks, dropping sharply to 10 months and more gradually thereafter; that mean

scores of girls were significantly above those of boys in the Down's Syndrome but not in the control group; that mean mental scale scores were significantly higher in the children of non-manual than of manual workers in the control but not in the Down's Syndrome group; and that mean scores of the boarded-out children were significantly below those of the home-reared.

That children with Down's Syndrome brought up in institutions are more retarded than those brought up in their own homes, even where the institutional environment is quite favourable, is now well established. (See page 5.) In spite of improved social services and social attitudes, which should help families to keep these children at home, it seems unlikely that the demand for out-of-home care for the babies will cease altogether. This being so, and as it is also unlikely that there will be enough families willing to foster these babies, there will continue to be a need for some sort of institutions to care for them. It may be important that those in charge of such institutions should receive support and advice, to save them from becoming discouraged ('What's the point of my doing my job' said one such woman, 'if all I'm doing is doing them harm?') and to encourage maximum development of the children; it might be helpful if some remedial programme were suggested, such as that used by Bayley *et al.* (1966) for use in the institution. Most of the homes or institutions in which the boarded-out children in the present study were placed did encourage the nurses to play with the children and to take them out, while in some the children were given quasi 'lessons' (though in some cases these amounted to little more than the children being given a ball-point pen and paper and encouraged to scribble). It seems likely that in order to be effective these 'lesson' periods would have to be longer, occupying more of the children's day; more structured, so that the children's activities were more positively educational; and should begin when the children were younger than were those in Bayley's study, with exercises and stimulation such as those outlined by Collins and Brinkworth (1969) from earliest babyhood. If programmes like these were followed by the staff of institutions the 'well established' difference between children brought up in institutions and in their homes might disappear.

It has also been suggested (Stedman and Eichorn, 1964) that mixing with normal children of their own age might be important in stimulating the development of young Down's Syndrome children in institutions—the writer too noted that, however good they might be in other respects, none of the homes to which the boarded-out children were sent contained other young normal children. However inspection of the scores of the home-reared children who did or did not have young sibs suggests that the presence of normal peers may not be of paramount importance. The mean scores of 15 children who did not have young sibs (under 11 at the time of the child's birth) were compared with the scores of 15 children who had 2 or more young

TABLE 3.12
Mean Scores of Children With and Without Young Sibs

	1.5	6	10 DIQ	Age (months)				MA
				15	24	36		
With sibs	85	70.6	48	48	35	17.6	21.9	
Without sibs	80	67	55	45	36	17.5	22.9	
Difference 'with sibs' minus 'without sibs'	+5	+3.6	-7	+3	-1	+0.1	-1.0	

sibs at birth. The results are given in Table 3.12. Table 3.12 shows that there was little difference between the two groups, although the difference at 4 years of 1 month in favour of those *without* young sibs might, if maintained, be considerable. Many of the mothers of the 'singleton' Down's Syndrome children, who, unlike those running the foster homes, had no other young children to attend to, devoted themselves with great energy to stimulating and educating their children. Evidence from studies on normal children suggests that the most important factor enabling a child to realize his full potential is an intensive one-to-one relationship with an adult, and it seems possible that this would apply also to the children with Down's Syndrome, and that this would be more important to their development than the presence of other young children in the home.

Finally, a question to which perhaps there is at the moment no answer: given that the intelligence level of young children with Down's Syndrome declines with increasing age, what causes the decline? Is it due to a deteriorating process which begins at or soon after birth? This view was held by Griffiths (reported in Kirman, 1969) although Kirman himself disagreed, while Bilovsky and Share (1965) took the opposing view that the decline might be due to statistical artefacts 'created by the increased psycholinguistic demands of later tests'. This sounds plausible, but is not borne out by the results of the present study. Here for example the greatest decline of scores took place between 6 weeks and 10 months, before verbal items became important. If, however, when verbal items did become important it was failure on these that contributed most to the decline of scores, then removing the verbal items should result in DQ's that decline significantly less. In the present study, removing the verbal items from the scores of the Down's Syndrome children at 10, 15 and 24 months resulted in *larger* declines of scores. The figures are shown in Table 3.13.

So it seems that in this study a relative weakness in verbal ability, together with the increasing importance of verbal items in intelligence tests, was not sufficient to account for the decline of later compared with earlier scores. Other items of which the tests are composed appear to have contributed at

TABLE 3.13
Mean DIQ's With and Without Verbal Items (home-reared)

	Age (months)			Decline in DIQ	
	10	15	24	10-15	15-24
With verbal items	49.1	47.8	34.7	1.3	13.1
Without verbal items	35.0	31.5	13.6	3.5	17.9

least as much to the decline; in these very young children no one item, or group of items, stands out as being particularly well or badly done by the Down's Syndrome children. The deficit seems a general one. This is not to say that we are forced into accepting the theory of 'diminution of previously possessed powers', as Bilovsky and Share put it. This would imply that the child with Down's Syndrome deteriorated from birth onwards, which does not accord with the clinical impression that he gives. The baby of ten months old does not strike one as being more defective than he was at six months, although it is true that he is able to achieve relatively less compared with the normal child. It seems more probable that the decline is 'due to a statistical or other artefact inherent in the structure of infant tests'. Kirman (1969) suggests that 'the measures of performance applied in the young infant do not reveal the full extent of the defect, which only becomes apparent when more sophisticated demands in the way of learning and social adaptation are made at a later stage in development'. If this were so, the question would arise as to whether this pattern of scores is peculiar to children with Down's Syndrome, or whether it might also be found in children with other types of retardation. Erickson (1968) who studied groups of children with unspecified disorders between 0 and 36 months, found mean scores that declined gradually from 57.2 to 48.5. Since these are ratio IQ's, and Erickson does not give details of the spacing of tests, it is hard to compare these results with those from the present study. Because of the relatively small numbers of other nosological groups, and of the difficulty of early diagnosis of most other types of mental retardation, few longitudinal studies of these have been made, and very few which give data as early as that available for the children with Down's Syndrome. But if comparable studies were made, they might throw much light on the vexed question of the reason for the decline of intelligence scores in children with Down's Syndrome.

Section II

The Family Study

4

Problems of Everyday Life

Bringing up a baby is no easy task. Young parents, especially with their first child, are often astonished by how thoroughly their lives are turned upside down by the advent of a baby. Advice and counsel on how to cope with the situation abound in books and magazines, infant welfare clinics and health visitors are there to help and so is the family doctor; but, unless they are unusually severe, any problems the baby presents are taken for granted as part of normal life, or anyway of normal family life. When however the baby is handicapped, there is a tendency to view all the problems he brings with him as unique and as related to his handicap. Obviously in some cases this will be so but it is not easy to predict exactly what special problems will be the result of his handicap. We might expect, for example that a child with cerebral palsy would have difficulty in walking; this may be so if the areas of his brain concerned with the functioning of his legs and with balance are affected, but otherwise, perhaps not. A mentally handicapped child may be expected to be especially difficult to toilet train, but is this inevitably so? In addition there are a number of myths, about Down's Syndrome children especially—they are happy, affectionate, music loving, stubborn children, given to mimicry, but how much of this is fact and how much legend? In particular there are a host of myths about the parents of handicapped children, who are seen as guilt ridden, isolated, over protective and rejecting of their handicapped child, neglectful of their normal children. (See Wolfensberger, 1967; Carr, 1974 for fuller descriptions of this stereotype.) We wanted to find out how far these ideas were true, and, especially, we wanted to find out what were the problems encountered by parents of handicapped children that went beyond those encountered by parents of normal children.

In the early days of bringing up a baby many of the problems have a practical down-to-earth quality—feeding, crying, getting the baby to sleep, doing the washing, are the first important problems and these are the ones we started with.

In spite of all the injunctions to be relaxed when feeding a small baby, for many mothers it is an anxious time, especially if they think the baby is not getting enough to eat. These worries were increased for the mothers of the Down's Syndrome babies; less alert, less eager for food and with weaker sucking reflexes than has the normal baby, they were sleepy, undemanding babies. They were difficult to breast feed, and only half of the mothers, compared with two-thirds of the mothers of controls, attempted it, while only 16 per cent continued with it after one month. This does not seem to have been due only to the fact that the mothers were older; mothers over and under thirty-five were equally divided into those who did or did not attempt breast feeding, while 59 per cent of mothers over the age of forty did attempt it. Similarly only a quarter of the mothers of Down's Syndrome children fed their babies on demand (compared with half the mothers of controls) mainly because so many just did not demand; 13 mothers of Down's Syndrome children said that the baby always had to be woken for a feed, or that he never cried or demanded a feed, compared with 1 mother of a normal baby. Thus the early feeding situation, which can cause worry to mothers of normal babies, was even more fraught with anxiety for the mothers of the Down's Syndrome children.

'He never cried, so I had to wake him every four hours. It was terrible. I used to spend an hour giving him two ounces of milk. He just wouldn't suck.'

'I fed her every four hours, but I had to wake her. She took a long time, about half an hour over an ounce or two ounces. Every time she was awake I would put a bottle in her mouth.'

'He slept all the time and had to be woken for feeds. He would sleep night and day if I let him. He would take an hour over his bottle and he does still.'

So bottle-feeding was the rule, and as they grew older the Down's Syndrome children remained dependent on the bottle for longer than did the normal children, and were less skilful at feeding themselves. In a few cases this may reflect a continuation of the lack of interest in food which the Down's Syndrome children showed as babies and where earlier some children had difficulty in sucking a few now had difficulty in chewing, or swallowing, or with lumpy foods (6 children at 15 months could take no solids except from a bottle). However the main reason for the difference in feeding ability probably lies in the difference in motor abilities generally between the two groups, especially at 15 months: at this time the mean motor age of the Down's Syndrome children was just over 8 months and many had not developed the skills of grasping and of control that are needed for self-feeding.

In view of the extra difficulties with feeding it is perhaps not surprising to find that three-quarters of the mothers of Down's Syndrome children would not allow them to refuse food (forcing or encouraging them to eat it, or saving

TABLE 4.1
Feeding and Self-Feeding (in percentages)

	DS (%)	Controls (%)	Level of significance (%)
<i>15 months</i>			
Still using a bottle	67	40	5
Having meals from a bottle	64	14	0.1
<i>Feeding self:</i>			
with fingers	34	95	0.1
with spoon, partly or completely	16	57	0.1
with cup, partly or completely	32	71	0.1
<i>4 years</i>			
Feeds self entirely	69	93	5
Eats ordinary (not minced or liquidized) food	77	98	5
Drinks alone	77	100	5
Does all three	64	93	1

the food until later and trying it again) compared with half the mothers of normals, and that 38 per cent were rated as anxious or concerned over feeding compared with 12 per cent of mothers of normals. Their increased anxiety is understandable; some of these mothers may well have felt that the baby could not be trusted to regulate his own nourishment, and that he might take insufficient, or even die of starvation, if his mother did not insist on his taking an adequate diet. Indeed perhaps the more interesting point is, not that more mothers of Down's Syndrome children were anxious, but that almost two-thirds of them were rated as unconcerned about the feeding situation. 'One of the others would have anything he left' was a comment heard from mothers of large families, and 'I don't bother, the dog has it so there is no waste', from the mother of an only child. These mothers showed considerable confidence in their child's ability to judge what he needed, a confidence which was similar to that of the majority—nine out of ten—of mothers of control children.

At 4 years too the Down's Syndrome children lagged behind the controls in their ability to feed themselves, but perhaps it is worth noting that two-thirds could feed themselves, eat ordinary family meals, and drink alone. So in spite of their children's relative backwardness, by this time feeding was no longer a major problem to most of the mothers.

SLEEPING

The majority of the children were little trouble to get to sleep, and there was no difference between the groups on this. Where they needed help this

usually consisted of rocking, cuddling, patting, or, at four, of stories or singing. Few of the children were given bottles or dummies; only 12 per cent of the whole group (Down's Syndrome and control children combined) were given either at 15 months, compared with 43 per cent of the Newsons' one-year-olds (Newson, J. and E., 1963). By four, only 8 per cent of the Down's Syndrome children and no controls at all ever had a dummy, compared with 14 per cent of the Newsons' four-year-olds (Newson, J. and E., 1968) suggesting a regional difference in the use of dummies between the Midlands and the South of England. As babies the Down's Syndrome children were less inclined to suck anything—thumbs, cloths, or toys—and less inclined to suck on going to sleep than were the controls so their lack of interest in dummies may reflect their general lack of interest in sucking.

Most of the children in both groups slept well. At 15 months about a quarter of the children in each group never woke at night, even when they were unwell, and by the age of four this number rose to about half. Two-thirds of the Down's Syndrome children and half the controls hardly ever woke, and only 5 per cent in each group woke more than two nights a week. By four years 23 per cent of the Down's Syndrome children and 39 per cent of controls woke at least once or twice a week. This compares with 20 per cent of the Newsons' normal 4-year-olds who woke as often as this. Most woke for only a few minutes; no Down's Syndrome child stayed awake for more than two hours, but one control child who had a severe sleeping problem habitually woke for more than two hours.

Asked, 'What do you do when he wakes?' almost all mothers said they went to the child; 10 per cent of mothers of Down's Syndrome children (and 13 per cent of mothers of controls) said they did not go, but in three out of the four cases this was because they had found that the child settled down by himself; 'He was asleep when I went in, now I leave him.' All the

TABLE 4.2
Sleeping at 4 Years Old

	DS (%)	Controls (%)	Newson normal 4-year-olds (%)	Hewett CP (%)
Woke often (2+ per week)	18	27	7	10
Woke 1-2 times per week	5	12	13	{54 36
Woke seldom	23	12		
Woke never	54	49	10xx* 73xxx 61x	36
Sleeping in parents' room	41			
Took a toy to bed	33			
Wanted a light	36			

* Levels of significance: x = 5% level.
xx = 1% level.
xxx = 0.1% level

other mothers took some active steps to quieten the child; half in each group changed his nappy or gave a drink, about a quarter nursed or comforted him, while less than 10 per cent took him into the parents' bed (compared with 33 per cent in the Newsoms' (1968) sample).

More Down's Syndrome children slept in their parents' room than did the controls and by four this was significant; in her sample of cerebral palsy children too, Hewett (1970) found 28 per cent sleeping in their parents' room compared with 13 per cent in the Newsoms' normal four-year-olds. Hewett postulates various practical reasons for this situation, but perhaps the major reason lies in the child's handicap and the parents' feeling that the child is still a baby and continues to need the help and attention that a baby gets. Fewer of the Down's Syndrome children wanted the night time comforts of a toy to cuddle or a night light in the bedroom. (This was not clearly related to where they slept; fewer of those sleeping in their parents' room took a toy to bed, but more had a night light—in neither case was the difference significant.) A third of the Down's Syndrome children actively resisted taking a toy to bed with them.

'She doesn't want anything with her, *Teddy* goes on the floor.'

That the Down's Syndrome children had less need of both a toy and a light in the bedroom may have been due to their less active imaginative powers; they may have been less apt to imagine terrors in the dark, and less likely perhaps to project a comforting personality on to a toy. On the other hand, O'Connor and Hermelin (1961) found that mongols obtained lower scores on tests of stereognostic recognition than did either normals or non-mongol imbeciles. They suggested that this might be due to either hypotonia, which would minimize kinaesthetic feedback; or to the coarseness, thickness and dryness of mongol skin. In either case the result may be also that the Down's Syndrome children derive less satisfaction from the actual cuddling and bodily contact with a soft furry object, which seems an important part of the normal child's reason for taking a toy to bed.

TABLE 4.3
Dressing

	Down's Syndrome (%)	Controls (%)	Level of significance (%)
Child gave some help with dressing, 15 months	24	69	0.1
Child gave no help with dressing, 15 months	47	12	0.1
Dressed self completely, 4 years	0	34	1

At both ages the Down's Syndrome children were reported as being much less helpful over their own dressing. Seven mothers of Down's Syndrome children and three of controls said the child was a positive hindrance in the dressing process.

'She undresses all the time whether we are trying to dress or undress her.' (Down's Syndrome child)

TOILET TRAINING

Toilet training is an important part of any baby's up-bringing, and one of the nightmares of the mother of a handicapped child is that he will be in nappies for ever. Nevertheless at 15 months there was little difference between the groups regarding toilet training, either as to when they were started on the pot or as to how much they used it.

About half the mothers in each group had started their children on the pot before they were 12 months old, with slightly more mothers of Down's Syndrome children starting before 6 months. A third in each group had not yet started the child on the pot by 15 months. Forty-four per cent of the Down's Syndrome and 29 per cent of the normal children were using the pot most of the time. Two-thirds of the mothers of Down's Syndrome children and half the mothers of controls felt that they should wait until either the child could walk, or sit more steadily, or until the weather was warmer (mentioned equally by mothers in both groups) or until he could speak well enough to ask for the potty (mentioned by 14 mothers of Down's Syndrome children, 7 mothers of controls) before they embarked on potting or went about it more strenuously.

The mothers were rated as to their attitude towards potting. 'Unconcerned' meant that they had not yet started potting the child, usually because they felt he was still too young, or were potting him only occasionally. 'Mildly concerned' meant that the child was put on the pot, but not very often (two or three times a day), he might be praised if he performed but no comment was passed if he did not. 'Very concerned' meant that the mothers potted the child frequently, night and morning, after every meal or bottle, some as often as every hour or two, and they might be angry with him if he were wet or dirty. The figures in Table 4.4 show that nearly half the mothers in each group were rated as unconcerned and only a minority as very concerned.

A few mothers who were rated at 15 months as unconcerned or mildly concerned clearly did not intend to stay that way. Two mothers of Down's Syndrome children and nine of controls gave some future date at which they would 'start seriously', 'really start', or 'get organized' on potting. To one

TABLE 4.4
Toilet Training

	DS (%)	Controls (%)	Level of significance (%)
<i>15 months</i>			
Started on pot before 6 months	33	12	
Started on pot 6-12 months	18	31	
Mother's attitude:			
Very concerned	13	12	
Mildly concerned	41	40	
Unconcerned	46	48	
<i>4 years</i>			
Rarely wet beds	21	83	0.1
Rarely wet or dirtied pants	38	88	1
In nappies, daytime	31	0	1
In nappies, night	67	7	0.1
Clean and dry by night	18	71	1
Used lavatory	20	90	0.1
Managed toilet alone	10	63	0.1

mother in each group starting training was to involve fairly heroic measures.

'I don't start them early but when I start I'll strap him in, he won't get up and walk away like some do.' (Down's Syndrome child)

'After our holiday next month I really will start, I'll put her on every hour or half hour.' (Control)

By four years old the gap between the two groups was wider, with the Down's Syndrome children significantly retarded in all aspects of toilet training. More control children rarely wet their beds or their pants, or dirtied their pants, more were clean and dry by day and both by day and by night. They far exceeded the Down's Syndrome children in their ability to manage their toileting by themselves and in using the lavatory instead of a potty. Nevertheless, the Down's Syndrome children had made progress. A small number had surpassed some of the normal children—38 per cent were clean and dry by day whereas 12 per cent of the control children were not. Three Down's Syndrome children (8 per cent) were doubly incontinent, whereas in Hewett's study of cerebral palsy children (Hewett, 1970) 24 per cent of those over 5 years old were doubly incontinent. So although toilet training is likely to take longer with a Down's Syndrome child than it does with a normal child there is little likelihood of really severe problems such as may arise with a cerebral palsied child.

There were no significant differences between the two groups regarding the mothers' attitudes to a toileting accident (wet or dirty pants). Less than a

quarter of the mothers in each group smacked the child for an accident, over half registered disapproval. Six mothers of Down's Syndrome children felt the child needed comfort after an accident.

'He's usually very upset so I sympathize with him, I never scold him. I say "Poor chap", and clean him up.'

INDEPENDENCE AND INTELLIGENCE AT FOUR YEARS OLD

An independence score, covering walking, eating, drinking, dressing and toileting at four years was calculated for each child; the lower his score, the more independent he was. Sixty-eight per cent of the controls but only 5 per cent of the Down's Syndrome children scored between 0 and 3; 98 per cent of the controls and 38 per cent of the Down's Syndrome children scored between 0 and 7. (Both differences significant at the 0.1 per cent level.)

For the Down's Syndrome children a linear correlation between their independence scores and MA at 4 years old on the Bayley Mental Scale was carried out; $r = -0.73$ (significant at less than the 1 per cent level). So the children with higher mental ages were more likely to be the more independent—a predictable finding. Inspection of individual scores showed that: some of the brightest children scored badly on independence (three children with MA's over 24 months had independence scores between 12 and 22); the moderately bright children had independence scores over most of the range, between 4 and 21; but all the very dull children, with MA's below 15 months, scored badly on independence, their scores ranging from 16 to 29. This suggests that although other factors (such as the mother's interest and effort) may affect the independence of the medium and high grade children, these are less likely to be effective for the most retarded children.

Until now we have been seeing how much more independent the control children were, and how far the Down's Syndrome children lagged behind them. It is useful to look more closely at the achievements of the Down's Syndrome children to see what they could do despite their handicap. By 4 years old nearly all could walk alone. More than two-thirds could feed themselves, eat ordinary food, and drink without help. Well over half (59 per cent) rarely dirtied their pants, and over a third (38 per cent) were virtually clean and dry during the day; nearly half (46 per cent) could manage toileting with a little or no help. On an independence scale nearly 40 per cent scored within the normal range for their age. So between a half and a third of the Down's Syndrome children were needing little more looking after in feeding, dressing, and toileting than do normal children of this age. In view of the severity of their handicap this seems a considerable achievement.

WASHING AND CARRYING

With children who are slower to become toilet trained and to learn to walk it was thought that the mothers of Down's Syndrome children would have more washing to do, and to find it more of a burden; and that they would have to carry the child more and be more likely to think of him as heavy.

Contrary to expectations fewer mothers of Down's Syndrome children felt they did a lot of washing even though they had larger families. It may be that, being older, they were more used to washing and took it more in their stride, and consequently did not think of themselves as doing a particularly large

TABLE 4.5
Doing the Washing and Carrying: 15 Months

	DS (%)	Controls (%)	Level of significance (%)
Did an enormous wash	34	69	1
Did an average wash	62	31	1
Found washing tolerable	83	69	

amount. Rather more of them found the washing tolerable: 'I don't mind it, it's a matter of course', or even enjoyable—'When it's fine I sometimes wash for fun'. As expected more mothers of Down's Syndrome children had to carry the child about a great deal—36 per cent compared with 7 per cent of mothers of controls. There was no difference in how heavy they found him, roughly a third in each group finding their children very heavy, quite heavy and tolerable. The Down's Syndrome children were at a rough estimate an average of 6 pounds lighter than were the controls* so the mothers of Down's Syndrome children were in fact finding their children relatively heavier than were the mothers of the controls.

The mothers' rating of the child's heaviness was not related to how much she had to carry him, or how heavy he actually was; about a third of each group of mothers who said they carried the child a great deal, sometimes or rarely, rated him as heavy, while an equal proportion of those children said to be very heavy or not very heavy actually weighed more than the average weight for this age.

* The mothers were asked to weigh their children before each visit, and, if they had done so, the weight was recorded. At 15 months the average weight of thirty-one Down's Syndrome children was 20 pounds (15 girls average 20 pounds, 16 boys average 19 pounds 14 ounces). The average weight of 30 control children was 26 pounds (15 girls average 25 pounds, 15 boys average 27 pounds 4 ounces).

Nothing that a small baby does is likely to have as much effect on his mother as his crying. A baby who cries a great deal, for long spells at a time, or whose crying persists in spite of everything that is done to comfort him, will exhaust, anger and perhaps even antagonize his mother. 'He screamed night and day until he was 6 months old. I used to have to put him down or he would have gone through the window' (control).

TABLE 4.6
 Crying at 15 Months

	DS (%)	Controls (%)	Level of significance (%)
Child cried often	0	10	
Child cried sometimes	18	12	
Child cried rarely	74	67	
'He doesn't'	8	12	
			5
Cause of crying: physical	69	40	5
Cause of crying: psychological	23	48	5
Soothed by: physical means	79	31	0.1
Soothed by: distraction	10	38	1
Physical cause soothed by physical means	93	41	0.1

There was little difference between the groups as to how much they cried; 4 controls but no Down's Syndrome child were said to cry often. Only 1 Down's Syndrome child and 4 control children were said to cry for long periods at a time, more than half an hour; the majority would cry for just a few minutes. The main causes of crying varied between the two groups; more of the Down's Syndrome children were most likely to cry because of some physical upset such as teething or other pains, hurting themselves, hunger or tiredness; more of the control children were most likely to cry over some psychological upset—not getting what they wanted, being bored, teased or frightened. The methods the mothers used to deal with the crying differed too; the mothers of the Down's Syndrome children were more likely to comfort the child, by picking him up, rocking him, giving him what he needed; while the mothers of control children were more likely to use distraction, giving another toy, sending him out into the garden, taking him for a walk. This difference was not due solely to the differences in the causes of crying; of the children in both groups crying for physical reasons more Down's Syndrome than control children were physically comforted. Slightly more mothers of control children usually ignored the crying (19 per cent compared with 3 per cent of mothers of Down's Syndrome children). 'I leave him to get on with it, he soon gets over it.'

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More mothers of Down's Syndrome than of control children thought that it would harm a child to be left to cry, but the difference is not significant. The two groups differed significantly in how long they were prepared to leave a child to cry before they went to him; more mothers of Down's Syndrome children would leave them no more than ten minutes—64 per cent compared with 40 per cent of mothers of controls. Only two mothers of Down's Syndrome and four of control children would let him cry for more than half an hour.

As the Newsoms (1963) also found in their survey, about a quarter of the mothers in both groups distinguished between different sorts of cry. 'Grizzling' or 'moaning' were thought not to merit the mother's going to the child, as neither were 'temper' nor 'tired' cries. 'A real cry', 'a distressed cry' would send the mother to him more quickly. A few mothers said that children of this age cried 'for devilment' or that they would get spoiled by being picked up or come to expect it. On the other hand 26 per cent of the mothers of Down's Syndrome children and 14 per cent of the mothers of control children said that if the children cried this showed there was something wrong, 'they don't cry for nothing'. The Newsoms (1963, page 85) found this point of view characteristic of their 'permissive' group of mothers. One young mother of a Down's Syndrome child oscillated between these two points of view, the permissive and the hard hearted.

(Do you think it does a child harm?) 'I think so, they are sort of calling for you. I don't say you should go in for every little whim. He's never cried unless there was something really wrong. Sometimes he tries it on, I go in and he laughs. I say "Right" and turn him over and leave him and he has another little cry.' (How long would you leave him?) 'Ten minutes. He really goes, his ears fill up with tears and he's sweating hot.'

Nearly a fifth of the mothers of Down's Syndrome children said spontaneously they would go sooner to this child than to a normal child. In one case this was because the child had a heart condition, and in three other cases because the child usually cried very little, 'so if she cries there must be something wrong'. One mother's reply sums up this attitude, and also the conflict between theory and practice in leaving children to cry.

'I don't think it hurts them. I wouldn't let *her* cry, but normally it is good to let them cry, they cry for devilment.' (How long would you leave a child to cry?) 'About ten minutes at the most. I say I'd leave them, but you don't, do you?'

In some cases the mother said it was her own feelings about his crying that made her go to the child as soon as she did. 'I don't know if it does him any harm, but it certainly does me, it gets me down.'

On the whole then it seems that the mothers of Down's Syndrome children had if anything rather fewer problems over their child's crying to contend with and that where it occurred it was more likely to have a

physical cause and to be manageable by physical means. It must be remembered that at the time of this interview (15 months) the average mental age of these children was about 9 months; so that their capacity for boredom and frustration (causes of crying mentioned mainly by mothers of control children) was more limited, as was their ability to play with a variety of toys and to take an interest in new surroundings. Whether or not this is the explanation for the difference between the two groups it might be useful to the mother of a young Down's Syndrome child to know that certain methods—physical ones—had been generally found more effective than others in comforting these children.

THE PROBLEMS AS THE MOTHERS SAW THEM

At 15 months the mothers were asked what were the biggest difficulties they had met with so far with their babies. Over half the mothers in each group spoke of some difficulty they had encountered; 36 per cent of mothers of Down's Syndrome children and 43 per cent of mothers of controls had had no or only minor troubles. Of those who had had problems, the difficulties encountered by each group were different; more mothers of control children spoke of sleeping difficulties—33 per cent compared with no mothers of Down's Syndrome children; three mothers of controls and one mother of a Down's Syndrome child spoke of crying as a problem, and although this is not numerically significant, to the mother of the Down's Syndrome child the crying was tiresome, to the mothers of the controls it was a major problem, involving doctors and, in one case, removal of the child to hospital. Three mothers of Down's Syndrome and five of control children spoke of illness as having been a problem, the interest here being that illness might have been expected to be more of a worry to mothers of Down's Syndrome children. More mothers of Down's Syndrome children spoke of feeding difficulties (40 per cent compared with 18 per cent of mothers of controls). Although this difference again is not statistically significant, the feeding problems of the Down's Syndrome children were more severe including four cases of serious difficulties in spoon feeding, never mentioned by the mothers of controls. Finally, in this study one problem belongs uniquely to the mothers of the Down's Syndrome children, and was mentioned by 33 per cent of them: that of the mother's feelings of distress at the child's condition, of disappointment, resentment and worry.

(What problems have you met?)

'Only that she was a little mongol baby, the disappointment when we had waited so long* for a baby.'

'The big one is knowing he is what he is. Once you get over that you just

* 14 years.

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accept him. The older he gets the more you notice his limitations. When other people notice it it doesn't worry me, I thought it would.'

'Meeting strangers and wondering if they had noticed it, and what to tell them. You are aware of other people's reactions all the time.'

'Adjusting to it, the shock. (Can you?) Not really.'

'The feeling of despair and worrying about it, the depression and the complete inability to cope. I used to wake up in the morning and think, what's the point in feeding her.'

'Wondering why this had happened to him when Bernadette is all right.'

'My own anxiety, facing up to it generally. It's later on that it will count, he's just a baby now. One changes, sometimes I feel it's no problem, sometimes I have a fear we may not like the outcome, he might not be accepted by everybody or we might not be able to cope. Everybody is very kind just now.'

No help from ingenious devices, services, or willing relatives, friends or professionals can dispose of this problem. It is all too real, inherent in the baby himself. Nor, obviously, since the mothers in the present study had had a good deal of contact with the professionals, and the opportunity for discussion and questioning, does a counselling service seem to be the answer. Nevertheless some such service might be better than nothing especially if it were designed to answer specifically the mothers' questions, and this will be discussed more fully in Chapter 11.

5

Behaviour and Discipline

All new babies are to some extent an unknown quantity in that we do not know exactly how they will develop or what they will be like as people. A mentally handicapped baby is even more of an unknown quantity, and the usual sources of advice—friends and relatives—may be no more knowledgeable than the parents themselves and no more able to lay down guide lines and suggestions as to how he should be brought up and his behaviour dealt with. We wanted to find out how the children's behaviour compared with that of their normal peers, and how their mothers dealt with it.

TEMPER TANTRUMS

A placid happy baby is easy enough to deal with, but problems arise when he becomes cross.

Temper tantrums are a normal part of most children's lives—14 per cent

TABLE 5.1
Tantrums and Their Causes

	DS (%)	Controls (%)	Level of significance (%)
<i>15 months</i>			
Had tantrums often	0	21	
Never had tantrums	44	15	1
Caused by frustration	59 (N = 22)	86 (N = 35)	5
Caused by compulsion	36 (N = 22)	6 (N = 35)	
<i>4 years</i>			
Had tantrums often	8	17	
Had tantrums rarely or never	39	37	

of the one-year-olds and 36 per cent of four-year-olds in the Newsons' samples had them frequently (Newson, J. and E., 1963, 1968). In the present study a temper tantrum was taken to mean the physical expression of an outburst of anger which lasted for at least a few minutes. Since it appeared at the beginning of the study that for some mothers 'tantrums' and 'crying' were exchangeable terms mothers who said their child had tantrums were asked, 'What does he do?' Tantrums were scored if some of the following behaviours were mentioned: kicks or stamps, screams, stiffens or throws himself back, throws or bangs things, goes red in the face, waves his arms about, or lies down on or throws himself onto the floor. At 15 months, more of the Down's Syndrome children were said never to have tantrums and more controls to have them frequently, but by the age of 4 there were no significant differences between the groups, the incidence of tantrums in both being lower than that reported by the Newsons (1968).

The mothers were asked what usually brought on a tantrum, and again the main reasons given were different for each of the two groups at 15 months but not at 4 years. Significantly more control children at 15 months had a tantrum because they were prevented from doing or from having something they wanted—'when he can't get his own way' was the characteristic phrase—or when things were taken away from them; slightly more Down's Syndrome children had tantrums when they were made to do things they did not want to do. Four controls and one Down's Syndrome child would throw a tantrum when they were not given the food or drink that they wanted; four Down's Syndrome children did the same when food they did not want was pressed on them.

In their handling of the tantrums, there was a tendency at 15 months for mothers of control children to be more punitive in their approach and for mothers of Down's Syndrome children to try to put right whatever was causing the tantrum, but the figures do not reach significance. By 4 years there were no significant differences between the groups as to what started the tantrum, or how the mother coped with it. The majority of tantrums followed frustration of some sort: when the child was teased or had things taken from him, or when he wanted to have or do something impossible (as when a child wanted to sweep up leaves with a broom that was too heavy for him). Altogether about 85 per cent of tantrums in both groups followed frustration of this sort. Two control children would throw tantrums when they were smacked or scolded, one after romps with his brother that got out of hand. Two Down's Syndrome children would throw tantrums if things were done in an unusual order—'milk before bread and butter instead of the other way round'—another when visitors—'you, or the man who comes to read the gas meter, anyone'—left the house, and another for no apparent reason, in the middle of meals or on the way to the bath. About a third of the mothers whose children had them ignored the tantrum, and a further third

scolded or punished the child. Thirty-six per cent of mothers of Down's Syndrome children and 27 per cent of mothers of controls tried to sort out whatever was wrong, or comforted or distracted the child.

Neither were there at four years any significant differences between the groups as to the incidence of tantrums. It is interesting that in the study of cerebral palsied children (Hewett, 1970) 22 per cent of the whole sample had frequent tantrums and significantly more children with mental handicap had daily tantrums—29 per cent compared with 9 per cent without mental handicap, suggesting that mental handicap is a factor making for more tantrums. However in the present study the mentally handicapped (Down's Syndrome children) had *fewer* tantrums than did the normal children, and fewer also than did the whole group of cerebral palsied children, so it seems that mental handicap does not of itself make for more tantrums. It is possible that the type of brain injury suffered by the cerebral palsied children increases the chance of tantrums commensurate with the increase in the degree of mental handicap, and that the mechanism affecting brain development in the Down's Syndrome children is a quite different one.

MISCHIEF

At 15 months the Down's Syndrome children were felt to be less destructive than were the control children, in that they interfered less with books and electric plugs. This is probably due to the fact that the Down's Syndrome children were less mobile than were the controls. When they were rated for mobility (on four items, ability to crawl, stand, step and walk with help) the more mobile Down's Syndrome children were found, as expected, to be the more destructive.

Over half the mothers of Down's Syndrome children and over a third of the mothers of controls said flatly that their children were not naughty, using such phrases as 'they can't be naughty at this age'. The majority of these mothers said that the children were not naughty at all while the remainder distinguished between the tiresome things the child might do and naughtiness:

'She's into everything, but that's not naughty.' (Down's Syndrome child)

'If he's doing something he shouldn't it's just that he's inquisitive.' (Control)

Of the Down's Syndrome children who were said to do naughty things, the most frequent complaint was of attacks on the mother and others, pulling hair, biting, scratching, and grabbing at glasses; this was followed by misbehaviour at meals, blowing, upsetting or throwing food, and these two categories accounted for two-thirds of all their naughtinesses. A few mothers

complained of attacks on furniture ('he bites the leather chairs') and of trouble over bath time or dressing, while only one said the child did things she had been told not to do. For the control children, attacks on the mother and misbehaviour at meals accounted for only a quarter of their naughtiness. Disobedience, going into cupboards, the fridge, or the oven, and emptying out what would be better left in its container—soap powders, sugar, ashes, coal—accounted for another two-thirds. Other naughty deeds mentioned were knob twiddling, 'bashing about', climbing, putting things in his mouth, and fighting with his brother, while tantrums were mentioned as naughty by one mother. Thus the Down's Syndrome children showed a much narrower range of misbehaviour than did the normal children. This must be accounted for partly by the fact that the Down's Syndrome children as a group were much less mobile at this age than were the control children: over half the controls, but none of the Down's Syndrome children were able to walk; all the controls were able to get about in some way, crawling, hitching on their bottoms and so on if they could not walk, but only a third of the Down's Syndrome children do so. This meant that a good many of the kinds of behaviours that mothers could think of as naughty, such as getting into cupboards or to knobs, coal scuttles, or dangerous situations, were not so available to the Down's Syndrome children.

By 4, more Down's Syndrome children were seen by their mothers as getting into more mischief than do most children and more were felt to do

TABLE 5.2
Mischief at 4 Years of Age

	DS (%)	Controls (%)	Level of significance (%)
Got into more mischief than most children	36	15	
Did mischief on purpose	46	17	5
Interfered with household objects	87	24	0.1
Got messy, dirty, etc.	15	49	1

these naughty things on purpose. The mischief the Down's Syndrome children got up to now mainly involved interfering with household objects; getting things out of cupboards (the largest single category, mentioned by half the mothers), pulling things down or upsetting them, tipping things out, touching things, fiddling with switches and plugs, putting things down the toilet—an inventory of trouble very similar to that encountered by the mothers of control children at 15 months. The controls on the other hand were now more likely to make a mess with water, damage the garden, or get themselves dirty in mud or coal bunkers. It seems likely that it was because

the Down's Syndrome children were still at the indoor exploring stage that they were thought to be so much more mischievous than the controls, who by now had largely learnt to leave household things alone. Climbing, and painting and scribbling, both on walls and on themselves, were fairly equally divided between the groups (21 per cent Down's Syndrome children, 17 per cent controls).

Most mothers felt that the children did these things because they were bored or showing off, or because they were interested, adventurous or inquisitive, or simply playing, and that 'mischief' was an unfortunate by-product. Others felt that their children deliberately set out to be annoying: the children knew that what they were doing was wrong, and the mothers felt this was obvious from the way the child looked at them, either before or after the wrong doing.

'In her heart she knows it's wrong, she'll look at me and stand with her hands behind her back.'

'She thinks about it, you can see that.' (Down's Syndrome children)

Two Down's Syndrome children would shut themselves into a room to turn it over.'

'If I'm cross, she'll go in and shut the door to do these things. It amazes me that she is so calculating.'

Although they were not more naughty at 15 months, the Down's Syndrome children were felt to be so at 4 years, and it may be that this comes about as the result of the lag in maturity, that their mental and physical capacities for naughtiness were not fully developed by 15 months but were by 4. The result was that the mothers of the Down's Syndrome children were faced with extra naughtiness at a time when this particular phase was a thing of the past for the mothers of the normal children.

AGGRESSION

Just over half the children in each group at 4 years old were thought by their mothers to be sufficiently aggressive, but not too much so, while of the rest slightly fewer of the Down's Syndrome children were thought of as aggressive, 21 per cent compared with 32 per cent of the controls. This finding may be of comfort to those mothers of Down's Syndrome children who fear, from what they have been told, that the child will be aggressive and spiteful; up to 4 years old he compares well with the normal child in this. Sixteen (41 per cent) of the Down's Syndrome children never got involved in quarrels with other children, partly because some were very passive children ('He's too easy going, he'll let other children take his toys') and partly because many did not have much contact at home with children of their own age (see

'Social Life for the Family and Community Contacts', page 82). Of those whose children did get involved in quarrels, most mothers in each group would try to mediate in the quarrels though several of these would try at first not to interfere and would only do so if things went on too long or too loud. About a fifth of the mothers in each group usually ignored the quarrels, either leaving the children to 'fight it out' or refraining from interfering because it seemed to do more harm than good. Most of the children in both groups could often, and some always, be left to settle their own differences with their companions, with girls rather better at this than boys; 38 per cent of those Down's Syndrome children concerned (those who ever got in a quarrel) and 22 per cent of controls could seldom be left to do so. There was no clear relationship between the child's aggressiveness and his ability to settle his own differences, though there was a very slight tendency for the more aggressive children to be left to settle it by themselves more often. Probably a good many factors enter into the situation, the temperament of the other child, how well they know each other, the mother's own tolerance of quarrelling; but perhaps the mother is less likely to interfere if she thinks her own child will do all right. As one control mother, who never interfered, said, with some satisfaction, 'They fight it out, and she always comes out on top.'

Three-quarters of the Down's Syndrome children never complained to their mothers about other children: probably the major factor here was their backwardness in speech as well as their passivity and fewer contacts with other children. Of the nine Down's Syndrome children who ever complained, seven had above average verbal scores on the Bayley, although one mother, whose child was one of the most advanced in speech, said, 'I have to ask the other one what it is, what has happened, because she can't explain. Then I have to give her the preference, because if she's in the wrong she doesn't come to me.' About a third of the mothers of complaining children tried to sort out the situation and another third (of control children) were unwilling to listen to the complaints because they smacked of tale telling. Four control mothers reacted to the complaints with 'What did you do first?' and four more and one mother of a Down's Syndrome child would tell them they must stand up for themselves; 'I tell him to go and punch them back'. In fact almost all the control children and the majority of the Down's Syndrome children would hit back if they were hit, and most mothers in both groups encouraged this (some said rather ruefully, 'We haven't had to encourage him, he does it anyway'). Ninety-five per cent of the controls and 82 per cent of the Down's Syndrome children hit back; 71 per cent and 53 per cent of the mothers encouraged them to do so with such comments as 'A child must be able to stand up for himself'. Of those whose mothers did not encourage this hitting, 22 per cent and 13 per cent respectively would encourage it in some circumstances, for instance if the other child were bigger or had started the

the fight. Ten per cent and 16 per cent respectively of the mothers would not encourage hitting back in any circumstances: 'I don't really want her to become like that.' 'She got a bit aggressive and I don't like that. If someone got something of hers I'd get it back for her.' (Down's Syndrome children)

So the Down's Syndrome children hit back rather less than did the controls and their mothers less often encouraged them to do so. They were also less often left to settle their own differences with other children, less often bidden to stand up for themselves, more often removed or distracted from the quarrel. Most mothers of normal children feel that they will have to look after themselves and stand on their own feet; especially with school approaching, where the child will not have his mother to help him, he must become able to fight his own battles. For the mothers of Down's Syndrome children the situation is different in two ways. First, since the child is developmentally so far behind, with a mental age of about half that of a normal child, he is that much less able to cope with quarrels and conflicts with other children—probably fewer mothers of normal children would expect them to settle their own differences at the age of 2. Secondly, the Down's Syndrome child is going to lead a life that will always be, to some extent, sheltered; he will never have to fend for himself as a normal child eventually will. If he goes to school, he will be under close supervision; he is unlikely to have to earn his own living, to live on his own, to run his own life. He will always be looked after. So the mother of a Down's Syndrome child may well feel that there is not the same need for him to become as self reliant as a normal child should, but that, on the contrary, the need is to guard against his becoming aggressive and incurring the dislike of those around him. These feelings may not be fully realized or expressed by the mother, but they may contribute to her attitude towards her Down's Syndrome child and his quarrels.

GETTING UPSET

Besides becoming angry or aggressive a child may simply become distressed. We asked the mothers what sort of things upset their children. More control children were upset by frustration and disapproval: if they were prevented from doing something, if things would not go just right or if they could not have their own way; or if they were scolded or 'If one of her friends says she does not like her'. Frustration and disapproval upset 54 per cent of controls but only 29 per cent of Down's Syndrome children. The biggest single cause of upset to the Down's Syndrome children was noise. Many sudden loud noises were mentioned—door bells, a dog barking, vacuum cleaners—but most frequently mentioned was human noise; shouting (not necessarily in

anger), calling, laughing and crying. Noise upset 38 per cent of Down's Syndrome but only 2 per cent of control children.

Most mothers comforted the upset child, or distracted his attention on to something else. A few mothers in each group either ignored him or punished him. In some cases the mother acts like this out of desperation—'I get in a bit of a state and end up smacking'—but in other cases, where the child is upset because he wants something he cannot have, she feels she should not give in to him.

So far we have been dealing with the various upsets and distresses shown by the children and how the mothers coped with these but that these were relatively infrequent occurrences is shown by the fact that at 4 years old 90 per cent of the children in each group were said to be happy children and only one child in each group was said to be a miserable child. About a quarter in each group needed much cuddling, and less than 20 per cent in each group needed less cuddling than do most children. So the Down's Syndrome children, who are often said to be particularly happy children, do not appear to differ from normal children in this respect..

EASY AND PROBLEM CHILDREN

Again in each group, over half the mothers found the child very easy to manage, while five mothers of Down's Syndrome children and six of controls found them so difficult as to constitute a problem. All the Down's Syndrome children whose mothers found them a problem had low-medium mental ages, between 17 and 22 months; none of the very low grade (and rather passive) children, nor of the brighter, more biddable children were found very difficult to deal with. With four of the controls and one Down's Syndrome child the problem seemed to lie in a battle of wills between the child and the mother; there were problems over eating and toilet training, the child was rude, attention-seeking and defiant. One control child was very clinging and another very mischievous. One Down's Syndrome child would not leave anything alone.

'He gets the cutlery out of the drawers, he moves heavy furniture about—he loves anything heavy—and the carpets, he twiddles the TV knobs. And he throws *everything*.'

With one Down's Syndrome child the problem was his temper and with another, 'To get through to him. I don't know what he wants. He just lies on the floor and grizzles'; and with another, the fact that he still needed a lot doing for him.

Punishment

At 15 months 68 per cent of mothers of Down's Syndrome children and 55 per cent of mothers of controls said that they did not punish their children and the question was in some cases followed by the kind of shocked silence so well described by the Newsoms (1963, page 104).

'We haven't punished her yet, how can you? They don't know, do they?'

'We can't (punish) because he doesn't understand. I think that is a very peculiar question.' (Down's Syndrome child)

'Oh I don't, he's too young. They can't be naughty at this age.'

'I don't really, she's not really naughty and she wouldn't understand.' (Controls)

The majority of mothers of control children and about a fifth of mothers of Down's Syndrome children who said they did not punish used some form of admonition, 'No', 'Naughty', or 'Stop it', when the child did or was about to do something they would rather he did not, although they did not regard him as being naughty. Significantly more mothers of Down's Syndrome children, 45 per cent compared with 17 per cent of mothers of controls, said they did not do even that much, that their children were not punished or scolded in any way. Of the mothers who said they did punish their children, the majority gave them what was variously described as a smack, tap or slap. 'Tap' suggests a much lighter form of punishment than the other two words (the Newsoms remark on this, and point out that in Nottingham 'tap' means a harder blow than it would in the South (1963, page 97)). In practice it was difficult to distinguish between the three words, especially as mothers sometimes qualified them, saying 'a light slap', or 'a slight smack'. Taking these qualifying words into account, of those who said they smacked their children at all, just over half the mothers of Down's Syndrome and just over a third of the mothers of controls specified that the smack was a gentle one.

The question of whether the child could understand the reason for his punishment was raised by mothers in both groups. Eight mothers of Down's Syndrome and two of control children said that they would not punish their children because they would not understand it.

'He might grab at something at table but I don't punish him, he doesn't know it's naughty.' (Down's Syndrome child)

'I don't really punish her, she wouldn't understand.' (Control)

Conversely two mothers of Down's Syndrome and six of control children felt that they should be punished since they thought that the children knew what they were doing was wrong.

'He pulls my hair and he knows he mustn't.'

'I tell her not to do something and then she does it. It makes me cross because she does understand.'

Two mothers, one in each group, gave opposite reasons for giving and withholding punishment. One mother said that the child was punished because this would teach him that the act which preceded the smack was wrong; the other said that she did not punish her little girl because she would not be able to connect her behaviour with the punishment.

'I put him upstairs in his cot and I smack his hand so that he knows it's wrong.' (Control)

'She's not naughty, she doesn't know she's naughty. She wouldn't know that you were punishing her for being naughty.' (Down's Syndrome child)

In the control group four mothers mentioned that they and their children sometimes became involved in retaliatory battles. Two children would smack their mothers back when they themselves were smacked; two mothers whose children would bite them, bit them back. Two other mothers, also in the control group, said that their children defied them, refusing to be dismayed by punishment and deliberately going back to evil-doing after it.

(How do you punish him?) 'It's a great problem. You smack his hand and he just grins at you. You say "No" and he just ignores that. You smack him quite hard and he goes back and does it again.'

'She's defiant, not naughty. When she's chewing her dress you can smack her as much as you like, she *wants* to defy me.'

Neither of these behaviours was mentioned by mothers of Down's Syndrome children.

By 4 years old when a child would not do as he was told his mother had a variety of possible responses to draw on.* She may 'give in', especially if she feels the request was unimportant, or she may ignore the fact that it was not carried out. She may not insist on obedience at the time, but return to it later, when the child may be feeling more co-operative. She may use verbal methods to get obedience: 'I try to make him, insist that he does it', or shout at the child. Or she may smack him. All these methods were used as a first resort equally by the two groups of mothers (90 per cent of Down's Syndrome children, 78 per cent of controls), with the verbal 'insisting' method accounting for half and smacking for another quarter of these in each case. To three mothers of very retarded Down's Syndrome children the situation did not arise: 'There's not a lot of telling with Luke.' Eight mothers of controls (20 per cent) but none of Down's Syndrome children would bribe the child into obedience or threaten him with a punishment; since both of these methods require the child to envisage the future and weigh up alternative advantages and disadvantages they may seem less

* Few were as unimaginative as the young control mother who said she smacked for all offences, adding helplessly, 'There's nothing much else you can do, is there.'

appropriate to use with the Down's Syndrome children (see section on Rewards, below).

In a more serious situation, if the child refused to do something he really must do, just under a quarter of the mothers in each group would still use the 'insisting' method—'I tell her and keep on telling'—while five mothers (three of Down's Syndrome, two of control children) who previously said they insisted would now shout. Most mothers (36 per cent of Down's Syndrome children, 46 per cent of controls) resorted to smacking. Seven mothers of Down's Syndrome and two of control children would use physical force, not necessarily unkindly, picking up a child who won't come, wedging a cup so that it won't be knocked over, holding a child down on the potty. Two mothers in each group would jolly the child into compliance, or sweep him along: 'I rush in and hustle her along as if I was absolutely going to tear the house down, rush her and bustle her along.' In the use of these methods there was no difference between the two groups of mothers.

Smacking

Rather more of the mothers of controls believed in smacking and more smacked in anger.

TABLE 5.3
Discipline at 4 Years of Age

	DS (%)	Controls (%)	Level of significance (%)
Mother believed in smacking	51	68	
Mother smacked only in anger	31	57	5
Mother rarely smacked	26	7	
Child sent to bed as a punishment	13	68	0.1
Child deprived of sweets, etc.	13	66	0.1
Child threatened with authority figure	3	20	
'I won't love you'	15	0	
'I'll send you away'	0	5	
Reward: Promised	38	61	
Sweet the reward	87 (N = 15)	59 (N = 25)	5

In both groups there was a tendency for older mothers (29+) and in the Down's Syndrome group for mothers of larger families (four or more children) to disapprove of smacking on principle but the figures do not quite reach significance. More mothers of Down's Syndrome children said that they rarely smacked their children—again there was a tendency, though not a significant one, for older mothers to smack rarely. When the two groups of

mothers were combined, more of those who said they believed in smacking also said they smacked only as a punishment (38 per cent against 13 per cent who did not believe in smacking). On the whole, those who did not believe in smacking were likely either not to smack at all (31 per cent) or to lash out when they were too cross to stop themselves (50 per cent).

Although the Down's Syndrome children were smacked rather less than were the controls they were not smacked less than were their own sibs. Smacking was consistent for the child and his sibs in 82 per cent of Down's Syndrome and 87 per cent of control families. In four families of Down's Syndrome children and in two of controls the child was smacked less than his sibs; in two families of Down's Syndrome children and three of controls, he was smacked more. It does not seem that, in the family, the Down's Syndrome child received much preferential treatment.

Both Down's Syndrome and control children were smacked sometimes for ordinary mischief (10 per cent and 15 per cent respectively) and for spitefulness or unkindness to other children (12 per cent in each group). The reason most often given was that the child would not do as he was told, or if the mother felt that the child knew that what he was doing was wrong, typically, 'If I've told him not to do a thing and he goes on and on doing it'. This applied particularly to the controls. Six controls were smacked for rudeness or for being troublesome at bedtime, five Down's Syndrome and one control child for getting themselves dirty or for toilet-training lapses, and five Down's Syndrome children for causing trouble at mealtimes.

About a third of the mothers in each group felt that smacking did not do any good, and 14 per cent of mothers of Down's Syndrome children and 8 per cent of mothers of controls felt that it was only helpful in the short term. Rather surprisingly there was no significant association between believing in smacking and thinking that it did any good: when the two groups of mothers were combined, of those who believed in smacking, over a quarter thought it did no good; of those who said they did not believe in smacking over half thought that it did some good. It seems that many mothers who dislike smacking on principle nevertheless found it a useful short term measure, that it did have the effect of cutting short the immediate naughtiness, although they were still doubtful of its value in the long run, or that it happened to suit the particular child.

'It stops her at the time, but whether she really understands I don't know.'
 'It works, but it doesn't really alter his behaviour.'

The reasons for the other type of inconsistency, believing in smacking yet thinking it does no good, are less clear, though again in some cases it seems that the mother felt that smacking did not suit this particular child.

OTHER FORMS OF DISCIPLINE

Rather slight differences then were found between the two groups on smacking but there were differences where other forms of discipline were concerned.

More controls were sent to bed or to another room, were deprived of something they liked (sweets, TV or any other treat) and were threatened with punishment from someone else (Daddy, the doctor, etc.). Only two controls and no Down's Syndrome child were ever threatened with being sent away. Significantly more Down's Syndrome children, half the group, were never given any of these punishments, compared with 10 per cent of the control children. This difference between the groups seems to be due to the different handling which the mothers feel a handicapped child needs; only 26 per cent of the mothers of Down's Syndrome children would give none of these punishments to a normal child. In their answers to the question, 'Would you ever tell a child you wouldn't love him if he behaved badly?' the situation was reversed; six mothers of Down's Syndrome children and none of controls would do this, which is surprising, since one would expect the concept of love and its projection into the future and dependence on the child's behaviour to be much less intelligible to the Down's Syndrome children, and to be used less by their mothers. All the mothers who told their children this were older than average (39+ at the birth of the child) and three of the six were foreigners (one Polish, one Italian and one West Indian) who may have different cultural traditions in this respect.

It may seem strange that a more violent punishment, smacking, was used on these mentally handicapped children, while milder kinds of punishment were not. One possible reason for this lies in the immediacy of the two types of punishment. A smack can be given immediately after a misdeed and the mother may feel that there must, therefore, be a connection in the child's mind between the misdeed and its consequence. But for banishment to bed, or deprivation of a treat, to be effective the punishment has to continue for some time after the misdeed is completed, and it may require some effort for the child to remember why he is in his room or why he may not watch TV. Parents may feel that this is beyond the capacity of a Down's Syndrome child and that, if he cannot properly connect the misdeed and the punishment, he will be less likely to learn from the experience. Another reason may be that the mothers feel the punishing effect of these types of discipline would be less powerful to a mentally handicapped child—that he might be less interested in sweets and TV or mind less about being put in his room—or indeed that he might wreck the room if he is put there as a punishment (*see page 59*).

It is interesting that the replies of these two groups of mothers differ from those in two other surveys, those of mothers of normal children living

in Nottingham (Newson, J. and E., 1968) and those of mothers of cerebral palsy children living in the East Midlands (Hewett, 1970). About twice as many Surrey children were sent to bed as a punishment as were Nottingham children; far more Nottingham children were threatened with loss of love or being sent away. Similarly far more of the cerebral palsy than of the Down's Syndrome children were given all these five punishments. In the latter case it may be that the different kind of handicap was important, and that most of the cerebral palsy children given these forms of discipline were mentally normal; there is little difference between the figures for the cerebral palsy and the Nottingham children. It may be however that there is a difference in approach to discipline between the two areas of the country, and that mothers in the South of England were as a whole less ready to use threats of banishment from their love or from the home than were mothers living in the Midlands.

The majority of mothers thought that a child should be made to say sorry, even if he did not want to, when he had been naughty. Eighty per cent of the mothers of control children would make him say 'sorry'; only 12 Down's Syndrome children had enough speech to make this possible, but eight of these mothers too would make him apologize.

REWARDS

Following the finding that more mothers of controls used bribes or threats to make the child do as he was told, it was not surprising that they were also more likely to promise him a reward for being good. As one mother of a Down's Syndrome child put it, 'We don't give her credit for being intelligent enough to understand', while another, who said she did promise rewards, added, 'but I don't think she realizes what it's all about'. The rewards were more varied for the controls; a sweet, ice lolly or ice cream, was the most usual but a toy, comic, book, outing or money were also promised. For the Down's Syndrome children, sweets were almost invariably the promised reward.

PARENTAL AGREEMENT

Two-thirds of the parents in each group were said to agree on almost all aspects of the child's upbringing: only two mothers of Down's Syndrome children and one of a control child said they seldom agreed. Agreement on discipline between the parents was similar for the two groups, though slightly fewer fathers of Down's Syndrome children were said to be more strict than their wives (23 per cent of fathers were stricter, 40 per cent of

mothers were stricter) compared with the controls (32 per cent of the fathers were stricter, 20 per cent of the mothers were stricter). A similar comparison was found between the normal and handicapped children in the studies in the Midlands (Hewett, 1970, page 105). So in the two groups of handicapped children, more mothers thought of themselves as stricter; in the two groups of normal children more fathers were thought to be stricter.

PERMISSIVENESS AND PUNITIVENESS

In an attempt to summarize the disciplinary methods of the two groups of mothers scores derived from their answers on relevant items (mother's attitude to sucking, whining, waking at night, sleeping, toilet accidents, tantrums, naughtiness, destructiveness, and smacking) were combined into a 'punitiveness—permissiveness' score for each mother. A comparison of the results showed that, first, up to 4 years, mothers of Down's Syndrome children tended to be less punitive and more permissive than were mothers of controls; second, that in both groups the middle class mothers were less punitive and more permissive than were working class mothers; and thirdly that although the differences were not significant there was a tendency in each group for older mothers (39+ in the case of Down's Syndrome children, 29+ in the case of the controls) and mothers of larger families (three or more children) to be less punitive and more permissive. In the mothers of the Down's Syndrome children there was a strong degree of association between the mother's age and the size of her family (2—older children, mothers aged 38—equalled 89 per cent, mothers aged 39+ equalled 33 per cent, significant at 1 per cent level). So one would expect the largest difference in permissiveness and punitiveness to be between older mothers of large families, and younger mothers of small families. This is in fact the case, though in view of the small numbers involved only one difference, in permissiveness at 4 years, was significant. In the control group the differences were much smaller but were in the same direction. Since only six control mothers had three or more older children, the comparison for the control mothers was made between those with 2+ and those with 1—older children; it may be that having two children does not bring about the increase in leniency which tends to be produced by three or more children.

It should be noted that the tendency of mothers of large families to be more soft hearted cut across, to some extent, the tendency for middle class mothers to be the more soft hearted, since there were fewer large families in the middle class. (Families of 4+ children, 15 per cent middle class, 29 per cent working class, combined groups.) So it seems that the most permissive, non-punitive situation for a baby would be as the fourth or subsequent child of an elderly middle class mother. The question of how far the child benefits

from either a tougher or a more lenient upbringing is not altogether resolved by this study. When the mothers were divided into those scoring more and less leniently at 4 years, proportionately equal numbers felt their children were easy to manage or were a problem, while in the Down's Syndrome group, there was no significant difference in the 4 year old mental ages of their children. In the controls, the 3 year old mental ages of children of mothers in the 'more lenient' group were on average five months higher, but as there were almost twice as many middle class mothers in this group this may have been the overriding factor. So no significant differences have been found in either the behaviour of the children or in their developmental progress between those who were treated more and less leniently. Within these groups of mothers the range of treatment may not have been great enough to show up in the children's development.

SUMMARY AND DISCUSSION

This part of the study attempted to discover how the mothers of Down's Syndrome children approached the business of bringing up their children, and how, if at all, their methods differed from those of mothers of normal children. At 15 months they tended to be softer, more permissive and child-centred, more comforting and less punitive, than were mothers of controls. This applied to their reactions to his crying, his naughtiness and his punishment, his destructiveness, and to a lesser extent his tantrums. This 'softer' attitude may have been brought about partly by the mother's feeling that the child was more fragile, more vulnerable, and more defenceless than a normal child would be, and certainly some of the remarks made by the mothers support this view. By 4 the gap between the methods used by the two groups of mothers had narrowed a good deal. Fewer Down's Syndrome children were deprived of sweets or sent to bed or threatened with an authority figure, but there was now little difference in the mothers' methods of handling tempers, or in the amount of smacking, or of how much the mothers believed in it (apart from smacking in anger). This increased toughness of the mothers was paralleled by increased tiresomeness from the children, who at 4 were having as many tantrums and were naughtier than were the controls. The mothers may have found that they had to use sterner measures. It may be too that the 4 year old Down's Syndrome child did not now seem so fragile and vulnerable as he had at 15 months; he now seemed to have a firmer grasp on life and need not be treated so tenderly. Perhaps it should be noted in passing that, although the differences between the groups as to the mother's handling were not significant at 4, yet they were in every case in the direction of gentler, less punitive treatment for the Down's Syndrome child. The progress towards equal treatment had begun, but was

not yet complete. It would be interesting to know whether eventually, when the children are older, these tendencies will be reversed; this is suggested by the work of Pitfield and Oppenheim (1964) who found that, compared with mothers of normal and of psychotic children, mothers of Down's Syndrome children were stricter in their attitudes.

It was unusual for mothers of Down's Syndrome children to use bribes or rewards to get the behaviour they wanted from their children, and at first glance the reasons the mothers gave for this, that their children would not understand what the rewards were for, seem reasonable. But there is every reason to think that behaviour modification techniques, involving the systematic use of reward and withdrawal of reward, would be highly effective in teaching these children a wide range of skills and in controlling undesirable behaviours. If the child shows a desirable behaviour, and is rewarded for it, he may not indeed at once understand what the reward is for: but if *every* time he shows that behaviour he receives that reward, eventually even the slowest child will come to connect the two and be more likely to show the desired behaviour. Behaviour modification techniques have not yet infiltrated into baby books for normal children; it is time they formed the basis for such a manual for the parents of retarded children.

6

The Effect on Family Life

Families are not static entities but constantly change as the members of it alter, grow older, acquire new interests, move away, and as new members are added to it. The arrival of a new baby changes the structure of a family profoundly, as each member adjusts his own position to include the baby and feels the effects of similar adjustments of the other family members. In practical ways too the baby alters the family's way of life; he has to be fitted in to the household so there may be less living space and the available money will have to be spread over an extra person. His needs for sleep, food, and play too have to be considered when the other family members plan their activities. These adjustments to some extent, are anticipated by the family and, as a rule, welcomed. When however the baby is not normal, new and unexpected kinds of adjustments must be made; expectations for the child and his future are thrown upside-down, and so to some extent the life of his family must alter too. We wanted to know what were the main changes that occurred, and in particular how damaging these were to the family as a whole.

TELLING THE PARENTS

Timing

The first major impact of the baby, as something different, may be felt when the parents first learn that he is handicapped. We asked the mothers when and how they learnt that their baby had Down's Syndrome and how they felt about the way in which they were told. Sixty per cent of the mothers had learnt of their baby's condition by the time he was a month old. This proportion is similar to that found in the younger group in the study by Berg *et al.* (1969) and higher than the 25 per cent told by one month in Drillien and Wilkinson's

TABLE 6.1*
Baby's Age When Mother Told of His Condition

Age	Satisfied with time	Preferred sooner	Preferred later	Total	Percentage (%)
0-7 days	11	6	2	19	41
8-30 days	8	1	0	9	19
1-6 months	5	8	2	15	33
7-15 months	1	1	1	3	7
Total	25	16	5	46	
Percentage	54	35	11		100

* Modified from Carr (1970). *Developmental Medicine and Child Neurology*, 14 (3), 205, by courtesy of the editor.

(1964) study. A third of all the mothers wished they had been told earlier than they were: only 12 per cent would have liked to have been told later. Six mothers who were told within the first week felt that they should have been told earlier still; all had suspected there was something wrong with their babies and had said so to medical or nursing staff. They felt they were then fobbed off with reassurances, or that information which they urgently asked for was withheld, or that they were told lies. 'As soon as she was handed to me she didn't look right. I asked the nurses and they said, "Oh all babies look like that".'

'My husband saw her eyes and asked if the baby was a mongol, and Sister said "It isn't for me to say".'

'I knew there was something wrong, he was floppy and his eyes looked Chinese. I asked the nurses and they said "He's lovely dear".' Although they had been told so early these mothers felt it was not early enough—'They should have told me when I kept asking' was a typical comment.

Fifty-six per cent of the mothers said spontaneously that they would rather know early on: 'It's best to be told early, then you know what to expect.' 'He had such feeding difficulties, if I had known he wasn't normal I'd have had more patience with him.' 'It was best to tell us in the beginning, it was bound to leak out.' Included in the 56 per cent are the six who specified that they should have been told the truth when they asked for it: 'The fact that it was hidden did us more harm than the fact of her condition.' Three thought that the parents, or at least the father, should be told as soon as there was any suspicion that the child was abnormal; two thought the doctors should wait until they were sure.

Who was told

In just over half the cases the mother was alone when the news was broken, and in only a third was it given to both parents together. Nine

mothers and one father (over a fifth of the whole group) discovered for themselves that their babies had Down's Syndrome. Most of these saw it in the baby's appearance or behaviour but in two cases the mother read the diagnosis in the hospital notes at the foot of her bed. In three more cases the father had already recognized that his child had Down's Syndrome before the news was officially broken. Altogether 18 of the mothers (40 per cent) had thought before they were told that there was something wrong with or odd about the baby. This agrees with the finding of Drillien and Wilkinson that nearly half of the mothers in their study realized before being told that there was something wrong with the child's development. In the present study six mothers thought the baby might have some illness, such as heart disease, spasticity or leukaemia, while another was afraid he had no arms or legs (she saw him only at two days old, well wrapped up, and was not allowed to hold him). Six noticed something in the baby's eyes or expression, and three that he was floppy or sleepy. One mother 'sensed something from the hospital's attitude', and a father said 'I knew people would not be so concerned if she were normal'. These last comments bear out the doubt expressed by Drillien and Wilkinson as to whether a mother's medical attendants 'will be able to act in such a way that her suspicions are not aroused'.

Shock

In 83 per cent of the cases the news, or the discovery, that her child had Down's Syndrome came as a shock to the mother, even where she had noticed there was something wrong. Of the six mothers who said that the news was not a shock to them, three had each discovered the child's condition for herself (one of these had been expecting the child to be abnormal ever since she found herself pregnant at the age of 50); one had thought the baby might be spastic and another had noticed something about the baby's face, and one already had a severely subnormal child and said that this lessened the shock for her. There were no differences between those told early or later (before or after one month); delaying the news of a baby's condition makes it no less of a shock to the mother when it comes.

Who did the telling, and how it was done

Much has been made of the question of who should tell the parents, especially in relation to the view that parents will feel resentful towards the one who tells them (Cowie, 1966). However half the parents in the present study said that they would be glad to see the teller again to discuss the baby,

and of the rest, most felt little need of discussion, and only four (9 per cent) seemed antagonistic towards the person who had told them. Of far greater importance than who does the telling is how the telling is done. Parents spoke extremely appreciatively of the way in which they were told in those cases where they felt that the teller was sympathetic, took trouble over the explanation, and answered their questions fully. They spoke resentfully when the doctor seemed to them unfeeling—'He carried on writing all the time he was telling me'—or if they were told abruptly, or were told the bare facts and then dismissed. 'She' (a woman doctor) 'told me the baby must have an operation, then she said he was a mongol, and she went out of my room and left me alone.' Where prognosis is concerned doctors are often warned against over optimism and raising false hopes, but in some cases it seems they go too far in the opposite direction and are unnecessarily discouraging. Some parents were given the impression that their child would never walk, talk, feed himself or become toilet trained. To engender such feelings of hopelessness in the parents is probably at least as unkind as it is to over estimate the child's future potential. 'We thought she would always be a vegetable. We had no idea she would be able to do all the things she has done. I think he (the teller) might have stressed the positive side a bit more.'

To sum up the parents' feelings about the initial interview: most want to learn of their baby's condition early, especially if they themselves have suspected something is wrong; they want to be told the truth; and they can be greatly helped to accept the truth if they are told gently and sympathetically and if they can return for further interviews for full information, questions and discussion.

FATHER'S PARTICIPATION

The mothers were asked how much their husbands had to do with their children; how much they helped to feed, change and bath them; how much they played with them, helped to get them to sleep and went to them at night if they woke, and how much they took them out on their own.

Feeding, changing and playing with the child were most often mentioned. Eighty-six per cent of the fathers in each group were said to play with their children often, and only one father (of a Down's Syndrome child, said to be 'very patient with older children but not a man for babies') never played with the child.* Four-fifths would feed the children, especially at weekends; three-fifths would change them and over two-thirds would help to get to sleep the children who needed help in this. Rather fewer would go to them at

* This child was also one of the most severely retarded of the children, with additional physical handicaps. A withdrawn child, who could not balance his head adequately or sit up, he was not perhaps a very promising partner for play.

night and about half would take them out on their own. There were no differences between the groups as to how much the fathers would do for the child, except that at 15 months fewer fathers of Down's Syndrome children would bathe the child, while at 4 more fathers often gave him his meals. The latter difference was probably due to the greater sophistication of the controls in feeding themselves, and hence in not needing feeding, but it is difficult to account for the former. Within the Down's Syndrome group significantly more of the fathers who would bathe the child were under 40 years old when the child was born; but if the difference in age accounts for difference in willingness to bathe the child it is difficult to see why this should not also apply to nappy changing, which traditionally is perhaps even more exclusively the mother's job, and in which however there was no significant difference between older and younger fathers. At 4 years old the father's participation both with the child and with his brothers and sisters is very similar between the two groups and similar also to that found in both the Nottingham study (Newson, J. and E., 1968) and in Hewett's study (Hewett, 1970).

TABLE 6.2
Fathers' Participation

	DS		Controls	
	Subject N = 34 (%)	Sibs N = 30 (%)	Subject N = 40 (%)	Sibs N = 38 (%)
Highly participant	53	63	58	51
Fairly participant	35	17	38	33
Not or not very participant	12	20	5	15

Fathers in both groups, although they did a good deal for their young children, tended to do still more for them when they were older: about a quarter in each group did little for their 15 month old children, but only 12 per cent and 5 per cent respectively did little for the 4 year old Down's Syndrome children and controls.

BROTHERS AND SISTERS

Over two-thirds of the sibs in both groups were easy children who gave no real trouble. In 14 per cent of the families of Down's Syndrome children and 31 per cent of controls the sibs gave some trouble at home; cheekiness, 'playing up', being self-willed, tantrums, tearing and scribbling on the walls, and, in older children, attempts at independence. The higher proportion in

the control families probably reflect the larger number of very young sibs in these families. Twin sibs of one control were in a boarding school for mal-adjusted children, three sibs were in more serious trouble; one, of a Down's Syndrome child, through shop lifting, two of controls at school.

Many parents are concerned that the presence in the family of a retarded child may in some way harm the other children, but most studies have found little evidence for this. (Barsch, 1968; Schipper, 1959; Caldwell and Guze, 1960; Tizard and Grad, 1961; Graliker *et al.*, 1962.) Holt (1958) found that 12 per cent of sibs in his study had suffered from the retarded child. Farber (1959) found that sibs were more severely affected by a young, very dependent child living at home, and that this affected normal sisters more than it did normal brothers—this latter finding was corroborated by Fowle (1968) especially as far as the elder sister was concerned. Gath has made two studies of the effect of a child with Down's Syndrome on the sibs; in the first (Gath, 1972) no significant adverse effect was found. In the second (Gath, 1973) comparing the sibs of Down's Syndrome with those of normal children, sisters of Down's Syndrome children were more often rated as anti-social by teachers; and brothers and sisters together, but neither separately, were significantly more often rated anti-social by parents. Other factors that contributed to the differences were age of the mother, family size and social class, and 80 per cent of the sibs of Down's Syndrome children compared with 90 per cent of the sibs of controls, were rated as non-deviant by both teachers and parents. So the evidence for a serious effect on the majority of sibs is not very strong, but parents who are worried about this might want to avoid laying too much responsibility on the normal daughters since it is they especially who may be at some risk.

In the Down's Syndrome group, of those mothers who had other young children (25) 16 per cent said they made no allowances for the handicapped child that were not made also for the other children. Of those who said they did make allowances, three-quarters felt that the other children understood why this had to be, 10 per cent that they resented it, and 14 per cent that they both understood and resented it. Nearly half the mothers thought that the other children were to some extent jealous of the handicapped child; half of these took no special steps about it, while the rest either tried to explain the child's need for more attention or tried to give the sibs extra love from time to time. Of those who did not think the other children were jealous many mothers said they tried to treat all the children alike (as did several of those who felt that the sibs were nevertheless jealous). In many cases the sibs were older, and the 4 year old handicapped child was still regarded as 'the baby', and entitled to privileges.

OCCUPATIONS AND PETS

The two groups of children had many interests in common, notably dolls and cars (among the favourites of over half in each group); building materials such as bricks and Lego, and large toys such as swings, slides and tricycles. Listening to music or looking at books was preferred by more of the Down's Syndrome children and painting, drawing and writing by more controls (about a quarter in each case). Favourite toys also differed; for the Down's Syndrome children these were often noise makers (rattles, humming tops, squeaky toys) and balls, which were among the favourite toys of 38 per cent but of none of the controls. Tools, pencils, plasticine and pastry were mentioned as the favourites of 27 per cent of controls but no Down's Syndrome children.

Just over half the families in each group kept a pet of some sort, and three-quarters of these children could be safely left alone with the pet. Three children in each group were liable to harm the pet; two Down's Syndrome and three control children might be harmed by it. In the case of one Down's Syndrome child there was mutual antagonism between herself and the cat.

THE MOTHER'S HEALTH

With all the extra worry and stress of a handicapped child coupled with their higher average age, it seemed reasonable to expect that the health of mothers of Down's Syndrome children would be poorer, and that they would be subject to more psychiatric illness, especially depression, than were mothers of controls. However no differences were found between the two groups on the mothers' ratings of their own health. Fifty-six per cent of mothers of Down's Syndrome and 63 per cent of mothers of control children said their health was good; one mother in each group said that it was poor. Slightly more mothers of Down's Syndrome children said they tended to get depressed—50 per cent compared with 44 per cent of mothers of controls; or run down—29 per cent compared with 15 per cent of mothers of controls; neither difference was significant. There were no significant differences in the medical attention that the mothers in each group had received. Just over two-thirds in each group had had no treatment; 18 per cent of mothers of Down's Syndrome and 15 per cent of mothers of control children had had tranquillizers, 12 per cent in each group had had tonics or other medicines, one mother in each group had been seen by a psychiatrist.

These figures are similar to those found in Hewett's (1970) study. Fewer mothers of cerebral palsy children—12 per cent—said that they were run down, but apart from this the mothers of Down's Syndrome children

tended to rate their own health as slightly better than did the mothers of cerebral palsy children.

Although the differences in health are not significant they are in every case in the direction of less good health for the mothers of Down's Syndrome children. The interesting point is that the difference in health is not more pronounced, and this is perhaps a tribute to the resilience of the mothers of handicapped children.

THE CHILD'S HEALTH

Children with Down's Syndrome are often thought to be particularly delicate, especially liable to chest infections and colds, and many mothers in the study had had the same expectations—'I thought he was always going to be chesty and snuffly.' We found that they had indeed had more ill health than had the controls, but not as much more as might have been expected.

TABLE 6.3
Illnesses and Health

	DS (%)	Controls (%)	Level of significance (%)
Had frequent colds	51	27	5
Rarely had colds	8	29	5
Tended to be constipated	38	17	5
Had at least one infectious disease badly	50	22	5
Had one infectious disease mildly or none at all	41	73	1
Had measles badly	50 (N = 18)	15 (N = 13)	
Mother rated child as:			
very strong	33	46	
average	54	52	
delicate	13	2	

The Down's Syndrome children had had more colds and constipation, slightly more coughs, bronchitis, diarrhoea and temperatures, while the groups were equal for other minor complaints—ear-ache, tummy aches, catarrh, and allergies—and more Down's Syndrome children had suffered from a number of these minor complaints. Of the infectious diseases—measles, mumps, chicken pox, German measles and pneumonia—more Down's Syndrome children had had them badly while more controls had had only one disease mildly or none at all. Measles and pneumonia had affected the Down's Syndrome children more seriously; of those who had had it, more Down's Syndrome children had had measles badly (the difference being not quite significant at the 5 per cent level) while nine Down's Syndrome

children had had pneumonia (and two more had died of it between 15 months and 4) but no controls. The Down's Syndrome children had caught more infectious diseases; 38 had had a total of 43 diseases, 41 controls had had a total of 32. Since the two groups of children had had roughly equal contacts with other children (see page 89), and therefore with possible sources of infection, it seems that the Down's Syndrome children did pick up illnesses more easily and tended to have them more severely than did the controls.

However there was no significant difference in the mothers' ratings of their children's health; about half in each group rated them as average and the majority of the rest rated them as 'particularly strong'. Only five mothers of Down's Syndrome and one of a control rated them as delicate. Many mothers of Down's Syndrome children had been warned that their children might be delicate; though they were asked in this survey to rate their child's health against that of his sibs or of other children whom they knew, they may also have been influenced by the fact that the child was, in many cases, more sturdy than they had expected him to be, and so to some extent have over-rated his health.

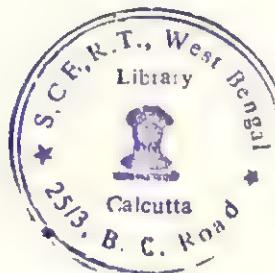
LOOKING INTO THE FUTURE

Nearly three-quarters of the mothers said they did not try to make plans for their children's future. Three were hoping their children would go to a boarding school when they were eight or nine, 'Somewhere where she can come home for weekends and holidays.' Three were considering the Camphill Villages or the N.S.M.H.C. Trustee Scheme. Two were saving money in case the child needed it in the future. Three had no definite plans, but thought about and discussed the future in fairly concrete terms with the rest of the family: 'We talk about it. Eventually she will have to go to a home, we don't want to make Christine or Caroline keep her. We want them to have her in a home and perhaps pay a little to make it a better one, not just a subnormality hospital.' 'I sometimes wonder about it (the future). Anne has said she'll take him if anything happens to us. I don't know if she would if she had children of her own.'

Those who did not try to plan all felt that planning was impossible until they could see how the child developed. For one mother the future was even more uncertain: 'We can't make any plans until he's had his heart operation. He might not live long enough to plan for him.'

Two mothers hoped their children would turn out to be above training centre level, and other mothers too probably had the same unexpressed hope. Others may have felt, with the mother quoted above, that the child might not live to grow up. Others again, between these two extremes, may have felt

that it was still too early to be sure whether the child would be so severely retarded as to be unable to contribute to his own support, or whether he would eventually be able to work in a sheltered workshop. In any case it seemed to them unrealistic to try to make plans for the future. As one mother said, 'Just hope is all I have for poor Veronica.'



7

Social Life for the Family and Community Contacts

In the last chapter we saw that having a mentally handicapped baby does not, at least when he is very young, seriously disrupt the life of the family within the home. Family life also goes on outside the home, in contacts with more distant relatives, friends, casual acquaintances and strangers. One of the stereotypes of the mother of a mentally handicapped child is that, worn out with the effort of looking after the child and too ashamed of him to take him into public, the mother withdraws from social life and becomes isolated and friendless.

LONELINESS

We asked the mothers whether, from their experience, they thought that having a handicapped child makes a mother lonely. Eight mothers (21 per cent) agreed that they had been lonely. The majority disagreed, some strenuously. 'Absolute nonsense. Nobody could be less lonely than me, and I've had a handicapped child all my life.' (This mother had a 25 year old severely subnormal daughter besides her son with Down's Syndrome.)

'Not these days. People seem to get very fond of Neil, I don't know if its just sympathy but I don't think so.'

Nine mothers felt that, far from making them lonely, their child brought friends to them.

'It's the other way round, everyone falls for Sarah, it's fantastic. She's invited to all the parties because people think she needs the company.'

'He's brought me a tremendous number of friends, he picks up people, they're terribly interested in him.'

Three felt that the children themselves were good company. 'I've been lonely since my husband was killed, I'd be lonelier without her.'

Of the eight mothers who felt lonely, two felt tied to the house, and one said that, since other children did not come to the house to play with her son, she herself did not meet their mothers as she might have done had the child been normal. One mother felt that her own sister had ostracized her since the baby was born, and one mother's social life had undoubtedly diminished because of her child's destructiveness; 'There's a wedding on Saturday, but I can't go because of Karen. I am asked, but she'd upset all the tables. We don't go out anywhere, we can't go into other people's houses, because she breaks everything.'

This mother and three others had found loneliness a considerable problem, but two others felt that they were getting over it, and two more that, if they were lonely, it was largely their own fault, 'There's no need for it really.'

HELP FROM RELATIVES AND FRIENDS

We asked how much contact and help the mothers had had from relatives outside the immediate family circle (husbands and other children) and from friends and neighbours. Their replies are summarized in Tables 7.1 and 7.2 and related to their loneliness.

Just over half the mothers said that they received some or much support from relatives and from friends. More mothers who said they were lonely said they received little or no support from either (57 per cent compared with

TABLE 7.1
Loneliness and Support from Relatives

	<i>Much support (%)</i>	<i>N = 38</i> <i>Some (%)</i>	<i>Little or none (%)</i>	<i>Total (%)</i>
Lonely	—	8	13	21
Not lonely	18	27	34	79
Total	18	35	47	100

TABLE 7.2
Loneliness and Support from Friends and Neighbours

	<i>Much support (%)</i>	<i>N = 38</i> <i>Some (%)</i>	<i>Little or none (%)</i>	<i>Total (%)</i>
Lonely	3	3	15	21
Not lonely	32	18	29	79
Total	35	21	44	100

17 per cent of those who were not lonely). Two lonely mothers felt that their loneliness was of their own making, and it may be that they discouraged the efforts of their relatives and friends to help them; the five mothers who were not lonely and received little support said emphatically that they did not need help and had not asked for it. Nevertheless the figures, although not statistically significant, suggest that where mothers are given much support from relatives and friends (the latter also seemed to be important) they are less likely to feel lonely.

The eighteen mothers who received little or no support from relatives included only three of the seven (five Irish, one Polish, one West Indian) whose own parents lived overseas—some of these mothers had brothers and sisters who had also come to Britain, and these were supportive to the mothers. Seven mothers said their families were too far away or too old to help, seven said they did not need help from them although they were confident they could get it if the need arose; ten felt that their relatives were especially warm towards this child: 'When I was in Ireland they all wanted Veronica, they were crazy about her.' Two mothers felt that the grandmother had not accepted the child (one insisted that her grandchild was normal) and one had never let her relatives know that the child had Down's Syndrome.

As far as friends and neighbours were concerned, one mother felt that some people had stopped visiting her after the child was born, and four mothers 'kept themselves to themselves'. The rest found their friends interested in and friendly to the child, making a point of speaking to him and asking after him—'They all love him, if they don't see him they miss him.'—and many offering to look after him or to give other help if it were needed. A quarter of the mothers had been offered this sort of help from friends and neighbours but some were chary of accepting it—'They've offered to have him but I don't like to, they don't know what he's like'—or the child, like any 4 year old, was too shy—'They're all very friendly, and one of them would have Gillian but she won't stop with them.'

Discussing the fact that some mothers who do not have many social contacts nevertheless do not say that they are lonely and vice versa, Hewett (1970) says: 'It seemed that feelings of isolation were much more a function of the mother's personality than of the presence of a handicapped child.' In the present study too, some mothers commented that their loneliness was their own fault. Nevertheless the highest proportion of lonely mothers was found among those who had the least support from relatives and from friends, and the lowest from those who had most support. It may be that mothers with a certain type of personality so discourage their relations and friends that they do not offer her their help, or it may be that the lack of helpful overtures results in the mother feeling lonely—possibly both play a part. But where a mother is offered and can accept support from those around her she seems to stand a better chance of not feeling lonely.

During the day at 15 months the Down's Syndrome children were less likely to be taken out visiting; here the age of the mother seems to be of some importance in that rather more of the younger mothers of Down's Syndrome children took their children out visiting than did older mothers, and where mothers of Down's Syndrome and control children were matched for age, the difference in visiting disappeared (see Table 7.3). At 4 it appeared that there was a difference between the groups as to how much the child was taken out shopping but this was due largely to the fact that more Down's Syndrome children were at school full time (see page 88); of those children attending school part time or not at all, there were no differences as to how much they were taken shopping. Nearly half the children in both the Down's Syndrome and control groups were often taken on other outings, to the park, or the seaside and so on; presumably these outings more often took place at weekends and so were not interfered with by school.

Evening outings were more restricted for mothers of Down's Syndrome children, both at 15 months and at 4. However there were no differences

TABLE 7.3
 Going Out and Baby Sitters

<i>15 months</i>	<i>DS (%)</i>	<i>Controls (%)</i>	<i>Level of significance (%)</i>
Daytime:			
baby taken visiting often	31	67	0.1
baby taken visiting often—mothers matched for age	76 (N = 17)	88 (N = 17)	
Evening:			
mother went out seldom	65	26	0.1
mother felt she went out enough	67	55	
Child looked after by sibs	33	5	5
Child looked after by other relatives	32	78	0.1
<i>4 years</i>			
Daytime:			
child taken shopping	46	71	5
child taken shopping, at school part time or not at all	62 (N = 18)	73 (N = 40)	
Evening:			
mother went out seldom	36	7	1
mother felt she went out enough	69	66	
Child looked after by sibs	41	10	1
Child looked after by other relatives	26	54	

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in the numbers of those who were contented with their situation, and in each case the typical comment was, 'We go out as much as we want to, we could easily go out more.'

Few parents—less than a quarter in each group—ever employed a paid sitter. At each age more of the Down's Syndrome children were looked after by a sib (more of them had older sibs) while more of the controls were looked after by another relative—usually a grandmother; the older age of the parents of Down's Syndrome children may have meant that there were not so many grandmothers still living to call on. Of those who said they would like to go out more, only three mothers said they could not afford to go out as much as they would like; these were middle class mothers none of whom employed paid sitters, so it was the cost of the outings not of the sitter that they could not afford. Five mothers of Down's Syndrome and two of control children found it difficult to get sitters, two mothers of Down's Syndrome and six of control children had sitters readily available, but did not like to impose on them by calling on them too often. The largest group—four mothers of Down's Syndrome and six of control children—consisted of those who felt in a vague sort of way that they would like to go out more often but had not bothered to do anything about it. Of those in both groups who felt that they went out enough, several mothers said they would not like to leave the children unless one of the family, or someone well known to the children was there to look after them, three fathers were not interested in going out and five mothers said they had plenty to do at home or were tired by evening and did not feel like going out. One mother of a Down's Syndrome child did not like leaving him at all and one mother in each group did not get on well with her husband and did not want to go out with him. So about three-quarters of the mothers in each group were not anxious to go out more in the evening, and only a few of the remainder gave the impression that they were fretting at having to stay at home. As the Newsoms (Newson, J. and E., 1963) say, TV has probably got a lot to do with it (and TV was mentioned by a few mothers as a reason for not going out) but reluctance to leave the children was another major reason for staying at home. 'We go out to important things, like Church Council meetings,' said one working class mother, 'but not for pleasure, our children are our pleasure.'

REACTIONS FROM STRANGERS

We asked the mothers of Down's Syndrome children whether, when they took the child out, other people stopped to talk to him, and how they felt about this. Two-thirds of the mothers said that other women would stop and talk to them about him, and none of the mothers said they disliked this. Many mothers said they preferred people to talk to the child than to ignore

him. 'In the beginning it was terrible, they wouldn't look in the pram. It used to hurt me when they didn't. I like it when they talk to her.'

'I do like it. I was quite surprised, I thought they'd turn away from him, but he draws them to me.' One-third found other mothers avoiding the child, and nearly half of these wished they would not.

'They shy away or stare, I'd rather they looked at him.'

Only 17 per cent of the whole group accepted avoidance by other mothers. Although some mothers disliked 'nosiness', or 'remarks', most mothers were glad of a friendly, interested attitude from other mothers, especially where this was accompanied by compliments—'They always say how sweet she is.'

HOLIDAYS

The family holiday is now an important annual event, which most families in all social classes expect to take. Over 90 per cent of the families in both groups had taken the child away for at least one holiday in the 4 years of his life time, and more than two-thirds of these had been away more than once. The majority of these holidays were a success, but 19 per cent of mothers of Down's Syndrome and 26 per cent of control children had had at least one unsuccessful holiday; this was 'mostly due to extraneous circumstances, such as bad weather, bad accommodation, or illness, but one family of a Down's Syndrome and three of control children felt that the holiday had been spoilt by the child.'

In Hewett's (1970) study, although the children were older, only 71 per cent had had at least one holiday in their life time. While differences in social class and, perhaps, in income between the two samples may have been partly responsible, it seems likely that the difference in handicap of the children would account for most of the differences in holiday-taking between these two groups. The majority of the Down's Syndrome children could reasonably be treated as, and be no more difficult to take on holiday than, ordinary children of half their age, but about one-third of the cerebral palsied children were severely physically handicapped, half of these being mentally handicapped as well. It is easy to imagine that the problems posed by taking one of these children on holiday, with all the extra difficulties over the bathroom and toilet, mealtimes, and stairs, might make it hardly worth attempting.

SOCIAL CONTACTS FOR THE CHILD

Besides meeting people when he is taken out shopping or on holiday, a child's main contacts with other children come either at school or when

children come to his home to play. At 4 years old over half the children in both groups were attending a school of some kind, but many more of the Down's Syndrome children were attending 'school' full time—18 children compared with one control child. Twelve Down's Syndrome children were attending Junior Training Centres, one child, whose mother was unmarried, was in a boarding school, coming home for weekends and holidays. The other 11 children were in play groups, normal nursery schools, and day nurseries, of which about half were fee paying. All but one control child were in part time play groups and nursery schools.

Transport to the school was no problem for most children in either group; one mother of a Down's Syndrome and two of control children found it difficult to get the child to school. Nine of the Junior Training Centre children were picked up and brought back by coach, two were taken in the family car, and one was near enough to be taken in a push chair.

Of the children attending school, more than two-thirds in each group enjoyed it, and their mothers thought it helped them. For half of the Down's Syndrome and a third of the control children, the main benefit that the mothers saw for them was in the company of other children, which helped them to mix better, stand up for themselves and to become less shy. Next for both groups came the activities they learnt, with feeding, toilet training and speech the most important for the Down's Syndrome children; handicrafts and drawing for the controls. Some mothers felt also that the schools gave the children more to do than they had at home.

Two-thirds of the mothers had visited the schools to speak to the teachers or head. Ten per cent in each group had not been because they thought they would not be welcomed or allowed in, but the majority felt free to drop in whenever they wanted to. However only a quarter of the mothers of Down's Syndrome children (and fewer of controls) felt that they had learnt anything from the schools that they could put into practice to help their children; for more than three-quarters of the mothers in both groups the boon bestowed on them by the school was free time; time to do the housework and shopping in peace, time to relax and be herself without always having to cope with the demands and the responsibilities of a small child.

'Day in, day out with her is very wearing. Now she goes to school I feel refreshed when she comes back.'

'I can have my hair done if I want to, or just look round the shops.'

'When he is at school I haven't got to worry about where he is or what he is doing, when he's here he's into everything.' (Down's Syndrome children)

Two mothers of Down's Syndrome children and one of a control did not enjoy their freedom.

'I didn't like it, I cried my eyes out, the house was dead without him.'

Three mothers of Down's Syndrome and five of control children did not have much free time mostly because their children went part time to school

At home, nearly all the children with brothers and sisters had a good deal of contact with their friends; only 9 per cent of Down's Syndrome and 20 per cent of control children never met their sibs' friends. In almost all cases where they did meet them, the friends would take an interest in the child, and over two-thirds in both groups would include him in some of their games—often these were of schools or hospitals, where a younger child fitted neatly into the role of pupil or invalid. However fewer Down's Syndrome children had a friend of their own, who came to the house just to play with him; 33 per cent of the Down's Syndrome and 73 per cent of control children had a friend of their own. Nor was it the case that those who were most at home were more likely to have a playmate; on the contrary 39 per cent of those attending school full time had a friend, compared with only 29 per cent of those attending part time or not at all. Only one of these friends was another handicapped child, the rest were normal.

Overall then the Down's Syndrome children had more contacts at school and fewer in outings to shops than did the controls, and other outings and contacts with their sibs' friends were roughly equal. The one significant difference lies in the numbers of children who had friends of their own come to play with them, and here the contacts of the Down's Syndrome children were indeed limited in comparison with the controls.

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Help for the Families

The advent of a handicapped baby often means that the parents are uncertain as to how he should be treated and what they may expect of him. Most parents need help with coping with their baby, and how much help they get and how useful it is to them probably varies with the individual child and his handicaps, the parents themselves and the services available locally to them. We asked the mothers of the Down's Syndrome children what help they had had with their children and how they felt about it.

SOURCES OF INFORMATIONAL HELP

A good many books and articles in magazines have been written about mentally handicapped children, and programmes about them appear from time to time both on radio and television. Two-thirds of the parents had read some books, booklets or articles on mentally handicapped children, and the majority had found these interesting or helpful. Three parents said they read 'Anything I can lay my hands on', one subscribed to magazines about teaching retarded children. Six had sent for pamphlets from the N.A.M.H., N.S.M.H.C. and Family Doctor, three had bought a book called *Teaching the Retarded Child to Speak*, by Julia Malloy (now alas out of print), one had read books by John and Elizabeth Newson and by John Bowlby from the N.S.M.H.C. library. Six had read *The World of Nigel Hunt* (Hunt, 1967), the autobiography of a boy with Down's Syndrome, which because of the level of literacy and competence that he achieved the parents found very encouraging.

Less than half the mothers had listened to radio programmes about mental handicap, 92 per cent had seen TV programmes on the subject. (This may reflect no more than the higher audience figures for TV generally; there had

also been two TV programmes specifically about Down's Syndrome children just before the study was begun.) Almost all mothers found the programmes interesting, but one-third did not find them helpful, either because the programmes did not apply to her particular child, or because they showed situations that were already sufficiently familiar through experience or reading. The mothers who found the programmes helpful liked their informative aspect, liked to see how the children grow up and what they can achieve (especially in the case of Nigel Hunt who was the subject of one documentary programme) and what is being done to help the children in various parts of the country.

VISITING HELP

All but one of the mothers had been visited at some time by the health visitor, although the visits had decreased as the children grew older; 50 per cent now never saw her and only four (10 per cent) saw her as much as twice a year. Out of the 19 still being visited, two-thirds were glad to see the health visitor, especially when she was able to give practical help, such as advice about feeding. Where the mothers were less enthusiastic about the health visitor it was usually because they felt that she did not have the specialist knowledge they needed.

'She never suggested anything, just said, how is he getting on.'

'She's very sweet but not very well informed, she doesn't know much about mongols.'

Over half the mothers (61 per cent) had been visited by somebody from the Health Department, either a doctor or a Mental Welfare Officer. These visits were usually connected with arranging for the child to go to a Junior Training Centre, and three-quarters of the mothers welcomed them. One mother, however, resented what she felt was the M.W.O.'s assumption that she would be thankful to have her child go to school.

'As regards the social welfare people, I didn't think her much of a help, they're only interested in getting them off to school and off the mother's hands—as if you wanted to!'

Another mother resented the Officer's readiness to prescribe for her child's needs before the child had even been seen: 'I rang them up and the man said, "A mongol? It'll be the Training Centre then." I said, "They do vary you know" and he said, "Yes, but it's most likely to be the Training Centre." The doctor came and she was very nice, but she only spent a quarter of an hour with him, on the floor, and then said coaxingly to me, "Shall I put his name down for the Training Centre? Just in case?"'

National Society for Mentally Handicapped Children

Only five mothers had ever been visited by anyone from the N.S.M.H.C., all welcomed the visits. Just under half the parents had already joined the Society. Over half of those who had not yet joined would like to, and one reason they had not done so was the difficulty of finding out about it. Only four mothers in the whole group had been told by the health visitor of the Society's existence, one by an almoner. The rest found out more or less by accident—four from friends, three from another mother, one sent for the Society's Christmas cards, one was told by the man who came to mend the washing machine. Just over half of those who had attended the Society's meetings found them helpful; not surprisingly they liked best those meetings which provided information that could be useful to them personally—about new schools, hostels, or holiday camps—but they also enjoyed the opportunity to talk to other mothers of handicapped children.

Of those who did not want to join the Society, two felt that they did not want to focus their lives on mental handicap but would rather mix as much as possible with normal people, two had been put off by the first meeting they had attended ('I want to join, but not the local branch') and one by her first contact with the Society: 'I rang the secretary, and she seemed very nice until I said I wasn't married, then she cooled off. I wasn't keen anyway, I didn't need much discouragement.'

Nearly 80 per cent of the mothers had met, one way or another, at least one mother of a mentally handicapped child. Three-quarters of these were glad to have done so, to learn from the other mother's experience, ask advice, compare their children, or just to 'laugh together over the things these children do—mothers of normal children wouldn't understand it'. Two mothers had been depressed by their contacts:

'Their children are all a lot older than Veronica and the mothers all tell me the bad things—how you can never go out, or, they're all right at that age, just wait until she is a bit older.'

It is interesting to compare the part played by the National Society for Mentally Handicapped Children in the lives of the mothers of the children with Down's Syndrome with that of the Spastic Society in the lives of mothers of children with cerebral palsy, reported by Hewett (1970)*. In the spastic group, 'more mothers had seen someone from the Society than from any other single agency,' while only 13 per cent of mothers of children with Down's Syndrome had ever seen anybody from the N.S.M.H.C. Thirty per cent of the mothers of the spastics had been approached in the first place

* It is important to note that the families studied by Mrs Hewett were those on the register of the Spastic Society's Families Help Unit in Nottingham, and so by definition were known to the Spastic Society. However, in Nottingham itself an independent register kept by the Health Department contained only one discrepancy from the Spastic Society's list, which suggests that here at least the latter may have been fairly complete.

by the Society; none of the mothers of Down's Syndrome had been approached by the N.S.M.H.C. (One mother who had had some contact through her work with the N.S.M.H.C. both before and after the birth of her son with Down's Syndrome was deeply hurt, after he was born, not to be invited to join the Society.) Eighty-three per cent of the mothers of spastics had been visited at least once in a year by the Society, 14 per cent of these three times or more; only one mother of a Down's Syndrome child had been visited twice by the N.S.M.H.C. Thirty-four per cent of mothers of spastics were told of their Society by doctors, hospital almoners or physio-therapists, compared with 13 per cent of mothers of Down's Syndrome children. It seems that the Spastic Society is more vigorous and more positive in its attitude to parents, and comes more readily to the minds of those in authority—perhaps because better publicized than the N.S.M.H.C. It is rather surprising then that there is little difference between the groups in their membership of the Societies—50 per cent of the mothers of spastics, 41 per cent of mothers of Down's Syndrome children were members of the relevant Society.

Other visits

In the Down's Syndrome group a few mothers had been visited by other agencies: four mothers (but only one of the ten Catholics in the survey) had been visited by somebody from the Church; three by a doctor's health visitor. One had been visited by the Red Cross, one by a doctor from a special clinic, and one by a doctor who had taken samples of the baby's blood.

The mother's attitudes to the visits

Asked whether they would like more visits from anybody, 82 per cent of the mothers said No. However, if they had not been included in the present survey, with all the visits that that entailed, three-quarters would then have liked more visits. Two-thirds of these would have liked such visits to be advisory, and a further 14 per cent both advisory and supportive. Clearly the majority feel in need of specialist advice. Many felt 'all at sea' with a Down's Syndrome baby, did not know what to do for the best for him, and felt that he posed special problems that common sense was not sufficient to solve nor could they rely on the experience of family or friends, as they could with their other children.

'I'd want to see somebody who knew something about it, and you wouldn't feel so alone. That's how I felt at first. Doctor — (a consultant paediatrician) said I could go to him, but he was always so busy.'

'It (visiting) helps parents of these children, *you* know what he ought to be able to do, and *you* understand, I can *talk* to you. At the beginning you're completely lost, *you* just don't understand. We were very worried, and the visits helped.'

Like these two, six more mothers felt that help was especially necessary when the child was small, while three felt that they would need help more particularly over schooling. To many of the mothers, an important aspect of the visits was that they showed that someone was interested in the child. Four mothers thought the visits helpful since during these they could discuss any small problem, when they would have not felt these justified a special appointment with their doctor.

'For anybody with their first or second child, it would be very necessary to have frequent visits. It would give you an opportunity to ask things. I often used to wish Miss — (the health visitor) would just drop in. I know I could always have got in touch with her.'

Several mothers would want comfort and reassurance—'Someone to tell me that some of them aren't too bad'—and three thought that they should have been told early of the possible sources of help, ranging from books and contacts with other similarly placed mothers, to information about schools. One mother, whose child was at first boarded-out and who was consequently not visited under the present survey until the child was two, summed up this point of view.

'When Kate was born we did not know about any of the things that were available, holidays, day nurseries or schooling, nobody seemed to know. The consultant said, "She's a mongol." We said, "What can we do?" and he said "Nothing, there's nothing you can do." It was the other mothers round here who told me she will be able to go to the nursery.'

HELP WITH CARING FOR THE CHILD— TEMPORARY CARE

Many authorities advocate that parents of handicapped children should be given the opportunity to take occasional holidays without him, and should be offered temporary care for him. Asked if they would allow their child to go into a residential unit to give the family a break, a third of the mothers said they would, though some said they would have to be absolutely certain that the child would be happy and well looked after. Three said they did not really feel they needed a break just now, three that they might allow him to go when he was bigger. Four including three of those who would themselves be quite glad to let the child go into short term care, said their husbands would never allow it. Three felt the child should not be 'pushed out' but should share in whatever holidays the family were having.

If an emergency cropped up, such as the mother having to go into hospital, in 28 per cent of the families the father would take time off work to look after the child; other relatives or friends would care for a further 46 per cent of the children; 21 per cent would probably have to go into an institution (40 per cent of those who would agree to temporary institutional care for holidays would accept it in an emergency, compared with 9 per cent of those who would not agree to it temporarily).

Thirty-six per cent of the mothers had been offered short stay accommodation for the child. Almost all of this was offered by hospitals, both sub-normality and general hospitals, though four mothers had heard of holiday homes, one through the N.S.M.H.C. and three through the Mental Welfare Officer. Two mothers had taken advantages of these offers for a holiday, but several mothers said their husbands were not keen on the idea. So at this early stage temporary care for the child was not seen as a pressing need for most families but it might become more important as the children grew older.

MEDICAL HELP

Genetic advice

Half the mothers had discussed with a doctor the question of having more children. Half of these had discussed it with their family doctor, the rest with a paediatrician or psychiatrist, none with a gynaecologist. Slightly more of the younger than of the older mothers had had the opportunity to discuss this, but the difference did not approach significance. Two mothers had discussed the question with their husbands but over a third had never discussed it with anyone.

Two-thirds of the mothers had not, before the birth of the child, wanted another child after him; following the birth of the child with Down's Syndrome, two of these felt that they would now like another child (and one had had another, normal, child). Of the 13 mothers who had wanted another child, five had changed their minds, and one of these had instead adopted a child. Of the eight who still wanted more children, four had had another child and two were still hoping for one, and two mothers were without a husband. Just over two-thirds of the parents were using some form of contraception; seven, including five who did not want more children, took no contraceptive precautions at all.

Help from the general practitioner

Half the mothers had found their own family doctor helpful. This meant, not that he could give any special help, but that he was willing to come and see the child, and in the majority of cases, took a special interest in him.

'He's very, very kind to John, nothing is too much trouble, though he's rather abrupt with ordinary people.'

'He comes without being asked and he always asks about her.'

'He'll always stand and talk to her and he never has to look up anything about her. I came out of hospital when she was 48 hours old and he came every day for a fortnight—mind you, I think he thought I was going to do the baby in.'

Two mothers did not take the child to the G.P. and the rest had not found their family doctor helpful; half of these (21 per cent of the whole group) felt that he was not at all interested in the child.

'Unless you've got a G.P. who's interested in mental handicap, you don't get any help at all. He can't cure what's wrong with her, so he doesn't take any notice of how she's getting on. A little of the bedside manner would go a long way with me.'

'Once she had a cold and I asked him to come and he said, "She's no different from other children just because she's a mongol." I was a bit annoyed.'

Help from clinics

Nine mothers had never taken the child to the Infant Welfare Clinic, and out of the 29 (76 per cent) who had, only five were still doing so. Of those who had attended, nearly three-quarters found the doctors and nurses helpful and a third of these stressed how kind the staff were. In three cases the clinic staff were particularly helpful; in one they told the mother the diagnosis for the first time, when the child was seven months old; 'They just said it straight out. After all that time and I had been taking her to the hospital, and they had never told me anything.' In another they discussed with the mother the enjoyable aspects of a child with Down's Syndrome and, when a baby sister was born, asked her to bring the Down's Syndrome child to the clinic as well; in the third, when the mother was too distressed to take her child to the usual afternoon clinic, the staff suggested she should come by herself in the morning.

Two mothers who had not found the clinic helpful thought the staff were more interested in the normal babies, and three were incensed by what they thought was a tactless attitude on the part of the nurses, who talked about the children in loud voices—'She kept saying "He's one of *those* children"

and they said "Is it obvious so soon?" and treated them as curiosities.

Half the mothers thought it would be better if there were a separate clinic for handicapped children; half of these (24 per cent of the whole group) because it would save the mothers the embarrassment of having other people stare at the child.

'A lot of these mothers, they're all young and they look at him and think "Oh there's something wrong with that baby".'

'I'm not ashamed of Veronica, but I think there are a lot of mothers who hate undressing their abnormal baby in front of mothers with normal babies. A lot say, "I hate going to the clinic, everyone looks at you."'

One mother was concerned about the distress she might cause other mothers at the ordinary clinic.

'I used to cry a lot and I thought it would upset them. And then I thought, the other girls couldn't rave about their own babies, how clever they were, in front of Gillian.'

The rest of the group favoured the separate clinic because they thought the doctors in them would be more knowledgeable, or that they would have more time to spend on the children.

Of the mothers who did not want a separate clinic, all but one (who was already attending a special clinic and did not find it much help) took the view that handicapped children should not be separated from the normal and that contact between them would benefit the children, their parents and the general public.

'It's better to have a clinic where all the children go and everyone can see them and get used to it.'

'People are learning to accept them now. If you were singled out in special places that's where you'd stay.'

Help from hospitals

Eighty-two per cent of the Down's Syndrome children had had to attend a hospital at some time, and 49 per cent were still attending at 4 years old. Two-thirds attended every three to six months, the rest once a year. Four children had attended once a month for a short time. Three-quarters always saw the same doctor at the hospital. In just under half the cases the doctor examined the child, usually listening to his heart or sounding his chest, and eyes, liver, teeth and walking were also mentioned. In five cases the child was tested, ranging from a full examination by a psychologist to 'a few elementary tests' given by the doctor. Two children were X-rayed, one weighed.

Twenty-two per cent of the mothers found these visits very helpful, a further 16 per cent quite helpful. The remaining 62 per cent (20 mothers)

found the visits not at all helpful. Six mothers complained that the doctors never discussed the child with them or offered them any suggestions or advice, four that the interview was so short compared with the length of time they had to wait for it, while four felt that the interviews were only useful in that the doctor could keep an eye on the child's progress.

(What does the doctor do at these visits?) 'He listens to his heart—he's got a flutter—and always assures me that he won't go to a normal school. "But mother" he says. It's just a routine, you don't get nothing from him. I'm in there two minutes and I have to wait an hour.'

'Nothing much. I think he was more interested in how I was reacting. They didn't say anything or tell me anything to do or not to do. It's more a nuisance than helpful.'

'Nothing. We're in there three minutes, he says "How is he? Good. Good." It's just a waste of time. I suppose it helps, they look through their notes.'

One mother was resentful that the hospital did not tell her that the child had Down's Syndrome, although she had taken him there several times. Two mothers found the hospital visits upsetting and worrying, one because she was told her child's heart was worse than it had been, and one because of the ineptitude of (presumably) inexperienced doctors.

'It was reassuring when we saw Doctor — but we were shattered when it was one of the other doctors. They did nothing at all, they looked at Gillian and they looked at me and asked a couple of questions that left me worried. They asked about her looking over the edge of the pram for toys that had dropped. Doctor — would say that she would do all these things in time, he knew she was backward. But the others we felt were completely unaware of what was wrong with Gillian, and if she would only look over the edge of her pram that would solve everything. We stopped going.'

OTHER FORMS OF TREATMENT SOUGHT

Eighty-seven per cent of the mothers had not sought any treatment or advice from anyone outside the Health Service. Two had consulted faith healers, one (who was herself Polish) had seen German and Polish specialists as well as taking her little boy to a faith healer. One had seen a Rudolf Steiner teacher twice. One had taken the child every four months to a homeopathic doctor for three and a half years, and paid four guineas a visit; she was doubtful as to whether the visits did much for the child, but 'We enjoy going, it encourages us.'

Eight mothers had thought about seeking other treatment but had never actually done so. The rest had not considered it, and many said that they had been specifically warned against doing so: 'Doctor — told us you can't do anything, no matter how much you pay.'

WHO WOULD YOU TURN TO FOR HELP?

Although this question added, 'other than about his health', 46 per cent of the mothers said that they would turn for help to a doctor, half to their G.P. and half to a consultant. Three of the nine mothers who would turn to their G.P.'s would do so although they found him unhelpful and only moderately interested in the child. Four mothers would turn to the health visitor, five to the Mental Welfare Officer, and five to the National Society for Mentally Handicapped Children, while the school clinic and Child Care Officer were also mentioned.

WHO WAS RELIED ON FOR HELP?

The question 'Who do you rely on most for help, at the moment?' seems to have been interpreted as meaning help with the day-to-day care of the child. A quarter of the mothers said they relied on no one apart from their husband. A third relied chiefly on their other children; these were mostly older children, some grown up and married, but one was a little boy of six, whom his mother relied on to keep her daughter with Down's Syndrome amused. In a family of children of both sexes the eldest daughter was usually the one relied on. Nearly a quarter of the mothers relied most on other relations, either her own mother or mother-in-law or sister: five (13 per cent) on a friend or neighbour. (Of the thirteen mothers who relied on relations or friends only two had other children over the age of seven, so sibs were less available to these mothers.) Two mothers said they relied most on their G.P., and no other social service or agency was mentioned.

HELP THEY WOULD HAVE LIKED

Nearly half the mothers could not think of any kind of help that they would have liked but had not had. 'No, I've been very lucky.' 'No, I've had quite a lot.' It is true that these mothers had had a good deal of attention from the present study which most mothers of handicapped children would be unlikely to get, so this proportion of contented mothers may be unduly high.

The largest single category of help which the mothers would have liked was of practical help, in looking after their children. Two mothers would have liked a nanny or a nurse, 'Just for her', six more would have liked to have known of a place that the child could have gone to occasionally or a person who would have taken him off the mother's hands for a bit.

'I would have liked somewhere I could leave him for short periods, not only for my sake but for the rest of the family.'

'I would like a break sometimes, someone to look after him for a bit.' 'When my husband died—looking back now I can see it was just as well I had her, it *made* me do things—but I would have liked someone who could take her for a bit.' (This child's father was killed accidentally at work.)

Another mother, who said she had not needed help with her son with Down's Syndrome, said she would have liked 'A day off occasionally', when her severely mentally handicapped daughter was young. This girl was now an adult, and the reason her mother did not feel in need of the same kind of help with her baby son is probably that she now had other young adult children; when she wanted 'a day off' from him, one of these children looked after the little boy. Similarly many other mothers of Down's Syndrome children received a great deal of help from their older children, and were surprisingly free to go out if they wanted to and to get the break they needed.

The other major category of help the mothers would have liked was more advice when the child was young, as to how to bring him up and train him, and as to the facilities available to help them. Several of these mothers said how hard it had been to get advice, that those to whom they had turned had not been helpful.

'You have to look for the help yourself. Our G.P. never suggested I took him to a hospital. I wrote to them myself.'

'Somebody who could really have told us and showed us, how to teach him, and at what age we should teach him.'

'Advice as how best to train her. I just had to fish around by myself. As it's turned out she's quite good, but I might have done her harm.'

'More knowledge from people, the clinic didn't help. We couldn't find out what was available, about homes, or Camphill, centres, one's rights in the matter, about training under Government-sponsored schemes, we had to ferret it out. When you have a child like this there's an abyss in front of you. We thought she would be a slobbering idiot. The sister said, "Oh I thought you were an experienced mother, I didn't think you needed telling." We attended Red Cross lectures and were told that she would develop at about one-third the normal rate. That was helpful.'

Two mothers wished they had had some domestic help, two that the child could have gone to a nursery, one for help with the child's speech. One mother still remembered bitterly the way the news of her child's condition was told, or not told, to her. 'The hospital should have told me he was a mongol as soon as he was born, as soon as they knew. They put me through hell not knowing, they kept fobbing me off. I knew something was radically wrong but I never thought of it being mental. I was so low by the time they did tell me I couldn't take it.'

One mother replied succinctly, 'A more co-operative family doctor.'

SUGGESTIONS TO PASS ON TO OTHER MOTHERS

We asked the mothers whether they had any suggestions that might be helpful to other mothers of handicapped children—'either practical suggestions for looking after their children, or on how you managed to face this and come to terms with it'. Most mothers had some suggestion to make, though four thought the situation was too personal, 'Every mother is different, there is nothing you can pass on,' and four could think of nothing to suggest, one saying, 'I could do with a few hints myself.'

There were few practical suggestions as to how or what the children should be taught, how to deal with their behaviour, how to handle the feeding and sleeping situations, and so on. (Perhaps the children were still too young for their mothers to have worked out many of these problems, but it seems more likely that they had encountered the problems but had not found any special way of dealing with them that was different from that with a normal child.) One mother spoke of emphasizing words and matching them to concrete objects and situations—'Say "cup of tea" when you give him one'—and another urged, 'Let them be with people, so that later they can be left sometimes.' Five mothers thought that the children must not be 'pampered' but must be allowed to try to do things for themselves, and two that training in each activity should begin as early as possible.

'To let her do whatever she can do and not frustrate her. Let her open doors and switch on lights and dress herself more. She has to learn to help herself, though with a handicapped child the slowness is very irritating.'

Three mothers thought that specialist books and magazines, contact with the National Society for Mentally Handicapped Children and with other similarly placed mothers were helpful. Four mothers looked back to the way they were told of the baby's condition, one with gratitude—'I accepted it right from the start. I'm glad I knew straight away,' and three with regret, especially that they were given so little information. Apart from these points most of the suggestions concerned the mother's attitude to her child, to herself and to the outside world; the kind of philosophy that was thought to be the greatest help to the mother of a handicapped child. By far the most frequently repeated suggestion, made by 11 mothers, was that the children should be treated as normal, and the next, made by eight mothers, that 'you just have to face it'.

'If it's definite stop fighting it and face up to it and bring them up as normally as possible.'

To one mother 'facing up to it' was more easily said than done.

'The hardest thing is learning to accept it. I found it awfully hard, I still don't think I have. I don't think you do, I still think I'll wake up and find he's different.'

Four mothers felt that the child should not be hidden away but should be

taken out as much as possible, to meet and mix with people, and that the mothers too must not isolate themselves. Four mothers spoke of the extra patience and perseverance that a child with Down's Syndrome demands, and others of the importance of love and of understanding, of keeping the child with the mother, and of the pleasure he can give.

'The only thing is to give them the love they need. Try to understand them. Face each day to see how they'll be that day. You get more pleasure out of them at this age than you do with a normal child.'

One mother spoke both practically and philosophically.

'I think I have trust in God, I think my religion did help a lot. More practically—just be very patient and persistent.'

9

The Effects of Social Class

In the Nottingham studies (Newson, J. and E., 1963, 1968) it was found that one of the most important factors determining the way a mother would behave towards her children was the social class to which she belonged. In this study an attempt has been made to see whether the same factor operated in the populations studied here. (One difference usually found between the social classes, that of the more rapid developmental progress of middle-class children, has already been found absent in this group of Down's Syndrome children.) The numbers in this survey were very small, and of course became even smaller when split according to social class. For instance the group of 39 Down's Syndrome children split into 19 middle class, 20 working class; the control group into 20 and 22 (20 and 21 at 4 years). Nevertheless some significant differences were found between the social classes even with these small numbers. In some cases, where the tendencies were similar, the middle- and working-class sections of the Down's Syndrome and of the control groups were combined. Only those areas where significant or consistent differences were found will be discussed.

HOME AND FAMILY

In both groups middle-class families were more likely to live in a house (rather than a flat or rooms), to have better standards of housing, and of washing facilities. In the control group middle-class parents were older than were working-class parents, but this was not the case with parents of Down's Syndrome children; mean ages at the birth of the child for this group were 36.8 and 36.6 for middle and working-class mothers respectively and 40.1 for both groups of fathers. There was a tendency for more working-class parents to have large families of 4 or more children and this was significant for the combined groups.

TABLE 9.1
Home, Family and Social Class

		Middle class non-manual (No. %)	Working class (No. %)	Level of significance (%)
Live in a house	Down's Syndrome	84	45	5
	Control	95	73	
Home very comfortable or good average	Down's Syndrome	84	35	0.1
	Control	95	14	0.1
Owned automatic or twin tub washing machine	Down's Syndrome	68	20	1
	Control	70	45	
No washing machine at all	Down's Syndrome	11	40	5
	Control	10	5	
Mother over 27 at child's birth	Control	80	43	5
Father over 27 at child's birth	Control	95	50	1
Families with 4+ children	Combined groups	18	41	5
Mother working; 15 months	Down's Syndrome	37	20	5
	Control	15	50	5
Mother working; 4 years	Down's Syndrome	42	30	
	Control	20	62	1

At both ages more working-class mothers of controls were doing at least part time work, while among the mothers of Down's Syndrome children slightly more middle-class mothers were working. Probably the difference in age between the two groups largely accounts for this. The majority of the (younger) control mothers either did domestic work to supplement the family income, or stayed at home to look after young children; in the Down's Syndrome group, with more senior fathers, there was perhaps less need for extra income among the working class, but mothers with specialized training felt more able to go back to their careers when most of their children were older, and when older children could take over at least part of the care of the baby.

Early feeding and comfort

In both groups more middle-class mothers breast fed their babies and more persisted with it beyond the age of one month. In the combined groups three-quarters of the middle-class mothers attempted breast feeding, compared with half the working-class mothers, while three times as many middle-class mothers were still breast feeding at one month (see Table 9.2.) This class

TABLE 9.2
Feeding and Social Class

		Middle class (No. %)	Working class (No. %)	Level of significance (%)
Attempted breast feeding	Down's Syndrome	63	40	
	Control	80	55	
	Combined	72	48	5
Breast fed for 1 month+	Down's Syndrome	32	0	5
	Control	40	23	
	Combined	36	12	5
Using bottle at 15 months	Down's Syndrome	47	85	5
	Control	25	32	
	Combined	16	35	
Fed on demand	Control	25	50	
	Combined	21	43	5
	Control	18	40	5
Baby sucked frequently	Down's Syndrome	0	15	
	Control	5	27	
Had dummy, 15 months				

difference in breast feeding was also found in the Perinatal Mortality Survey and National Child Development Study (Butler, 1971).

Many differences between the social classes found in this and in other studies (in housing standards, access to labour-saving devices, nursery schooling and so on) may be ascribed simply to different levels of income, but the differences in breast feeding run counter to expectations on economic grounds: middle-class mothers, with more money available, breast feed their babies which costs nothing; working-class mothers, with less money, bottle feed their babies using bottles, teats, milk powder, and fuel, all of which have to be paid for. The reasons for this difference have been well discussed by the Newsoms (Newson, 1963, pages 171 to 177). They suggest that middle-class mothers, more influenced by the advice of baby books and professionals which extols the values of breast feeding, feel they ought to breast feed the baby and feel guilty if they do not; working-class mothers, on the other hand, who are more prudish about nudity in general, dislike exposing their breasts for feeding, and because of poorer housing conditions are less likely to be able to do so in privacy. In addition a bottle fed baby can be fed at any time, even if the mother is busy, by propping the bottle on a pillow; the mother can then get on with her work, and is less likely to feel guilty of depriving the baby of contact with her than is the middle-class mother. So, in times of plenty, the cost of bottle feeding is to a working-class mother a small price to pay for the gain in privacy and freedom, while middle-class mothers breast feed their babies on principle. These are persuasive arguments and seem to explain adequately the class differences in infant feeding.

Working-class Down's Syndrome children used a bottle longer and there was a similar but insignificant difference within the control group. Twice as many working-class mothers in each group fed their babies on demand; more sucking (of thumbs, cloths etc.), was reported of working-class babies; and of the very few who had a dummy at either age, rather more were working class. So, although middle-class children in both groups were more likely to have been breast fed, working-class children were more likely to have been allowed other forms of sucking experience.

No differences between the social classes could be found at 15 months or at 4 years regarding self feeding or the mother's attitudes to the refusal of food.

Dressing

At 15 months more working-class Down's Syndrome children could help with their own dressing, and at 4 this tendency was seen in both groups though now much less pronounced in the Down's Syndrome children.

Toilet training

Middle-class mothers went about toilet training more vigorously than did working-class mothers; they tended to start the child on the pot earlier, and at 15 months had rather more success in getting their children clean and dry. In spite of all these efforts, at 4 years old fewer of their children, only a quarter, could manage the toilet by themselves compared with nearly half the children of working-class mothers.

However, perhaps we should not conclude from this that vigorous early training has poor results later. It may be that mothers who are concerned about early training continue to offer help later, while mothers who are

TABLE 9.3
Dressing and Social Class

		Middle class (No. %)	Working class (No. %)	Level of significance (%)
Child gave some help with dressing, 15 months	Down's Syndrome Control	28 95	75 82	1
Dressed self with little help, 4 years	Down's Syndrome Control	16 50	25 71	

TABLE 9.4
Toilet Training and Social Class

		Middle class (No. %)	Working class (No. %)	Level of significance (%)
Started on pot before 15 months	Down's Syndrome	74	60	5
	Control	85	50	
Used pot usually, 15 months	Down's Syndrome	53	15	5
	Control	30	9	
Needed no help with toilet, 4 years	Down's Syndrome	5	15	5
	Control	45	81	

unconcerned earlier are more prepared later to let the children get on by themselves. The reports we are getting here may be more of the mother's than of the child's behaviour.

Sleeping

At each age more Down's Syndrome children of working-class mothers slept in their parents' room, but this was true of the controls only at 15 months. Middle-class mothers were more willing to spend time in soothing and settling their child to sleep: at 15 months if he cried when he was put to bed, there was a tendency for more middle-class mothers to soothe him, by rocking or nursing him and so on, and for working-class mothers to leave him to cry; while at 4 more middle-class children were 'helped to sleep' by cuddling, singing, stroking, story-reading, immediately before they were left. Again at 4, more of the middle-class children were allowed some light in the bedroom—usually either a night-light or the landing light coming through the open door—until they went to sleep.

There were at 15 months no other night-time differences between the groups except for the participation of the fathers: middle-class fathers of both groups were more likely to go to their children when they woke. It may be that, just as the Newsons (1963, page 220) found that working-class fathers, who spend their day in heavy physical exertion, are given first consideration by their wives where feeding is concerned, so sleeping may be seen to be of paramount importance for these fathers; while middle-class fathers may feel that their working day involves no more physical effort than that of their wives and that they should take a fair share of getting up at night. Other significant differences in the fathers' participation were found in Nottingham, with social class in general correlating positively with participation (Newson,

TABLE 9.5
Sleeping and Social Class

		Middle class (No. %)	Working class (No. %)	Level of significance (%)
Slept in parents' room, 15 months	Down's Syndrome Control	21 20	65 41	1
Slept in parents' room, 4 years	Down's Syndrome Control	16 10	65 10	1
Child cried, would soothe him, 15 months	Down's Syndrome Control	84 85	75 55	5
Child cried, would leave him, 15 months	Down's Syndrome Control	16 15	25 45	5
Helped to sleep, 4 years	Down's Syndrome Control	37 50	10 34	
Light in room, 4 years	Down's Syndrome Control	53 75	20 48	5
Father went to child, 15 months	Down's Syndrome Control	62 83	50 39	1

J. and E., 1963, 1968) but in the present study no other significant difference in fathers' participation was found at either age.

If middle-class mothers are less apt to worry about nudity than are working-class mothers, they are more likely to be disturbed by slow weaning and toilet training. Apropos of toilet training, the Newsoms remark 'Any woman who has an automatic washing machine will testify to the dramatic effects that this has upon her ability to show equanimity when her toddler continues to wet nappy after nappy' (Newson, 1963, page 158). But it was the middle-class mothers, who had more automatic machines, who started the child on the pot earlier. Further, of the middle-class mothers in the combined groups, a higher proportion of those who owned an automatic machine started the child on the pot before 12 months. So the urge to toilet train the child was clearly not related to the facilities available, and was probably related to different class attitudes; middle-class mothers seemed more likely to be ashamed of having an older child still in nappies. It may be that this, together with the wish to wean the child early, was related to a dislike of the 'in-between stage', and an urge to hurry the baby into childhood. It is not the bottle itself that worries the mother but the use of it when she feels it 'ought' to have been given up; nappies are accepted for a small baby, but a toddler 'ought' to be out of them. In both cases, an older child sucking

a bottle (even more a dummy) or still in nappies is evidence that a desirable stage of maturity has not yet been reached. Since, as we shall see, it seemed that middle-class mothers tended to feel that most aspects of child behaviour were to some extent under their own control, a late maturing child may have been felt to be in some way shameful, and these mothers were prepared to make strenuous efforts to avoid this.

TABLE 9.6
Discipline and Social Class

		Middle class (No. %)	Working class (No. %)	Level of significance (%)
Mother punished or ignored a tantrum, 15 months	Down's Syndrome	39	67	5
	Control	42	68	
	Combined	41	68	
Spanked naughty child, 15 months	Down's Syndrome	21	45	5
	Control	25	45	
	Combined	23	45	
Comforted upset child, 4 years	Down's Syndrome	68	60	5
	Control	90	52	
Punished or ignored upset child, 4 years	Down's Syndrome	26	35	5
	Control	5	43	
Watched child little, 15 months	Down's Syndrome	42	55	5
	Control	25	55	
Could be left for more than a few minutes, 4 years	Down's Syndrome	79	50	5
	Control	90	71	
	Combined	85	61	
Child mischievous, 4 years	Down's Syndrome	21	50	5
	Control	5	24	
	Combined	13	37	
Child aggressive, 4 years	Down's Syndrome	11	30	5
	Control	20	43	
	Combined	15	37	
Father rated stricter	Down's Syndrome	16	30	5
	Control	15	48	

Discipline

On the whole working-class mothers were more likely to punish their children and to think of them as troublesome. At 15 months more working-class mothers punished, scolded, or ignored the child with a tantrum, and more spanked him when he was naughty.

At 4 the trends were similar but not significant, but when the child was upset more middle-class mothers, especially control mothers, comforted or distracted him, whereas working-class mothers were more likely to punish or ignore the upset child. There were no consistent differences as to whether the mother believed in smacking.

At 15 months more working-class mothers watched the child little, but by 4 more middle-class children in both groups could be left for some time on their own while the mothers got on with other jobs, supporting the Newsoms' (1968) finding that working-class children are more likely to dislike playing on their own. More working-class mothers in both groups thought their children got into more mischief than do most children, and more working-class children were said to be aggressive.

In both groups fathers were rated as stricter by more working-class mothers. This was also found by the Newsoms (1968) and they comment that this was not because fathers further up the social scale were more easy going but because these parents agreed on discipline. In the present study this tendency was found in the control but not in the Down's Syndrome group.

In many of the areas discussed an important difference between the two social classes seems to lie in the degree to which the mother involved herself with the child and with his day-to-day activities. Middle-class mothers seemed more closely concerned with all the child did, while working-class mothers were more likely to leave him alone and let him get on with it. This would help to explain why working-class children achieved independence in feeding, dressing and toileting earlier than did middle-class children; not necessarily because they were more advanced but because they were given less help with and more opportunity to do these things for themselves. Middle-class mothers 'helped' the child to sleep; working-class mothers put the light out. When he was upset, in a tantrum, or (to a lesser extent in this study) quarrelling with another child, the middle-class mother was more likely to try to put things right, the working-class mother to ignore it. The working-class mother seemed more ready to leave matters to the child and to fate, whereas the middle-class mothers seemed to feel that her active participation in the child's affairs was necessary; she seemed to feel too that by her own efforts she could shape the child the way she wanted him (for instance in deciding how much sucking he should have, or when he should be toilet trained). So the middle-class mothers seemed to make more attempt to con-

trol the child's behaviour, working-class mothers to leave him to his own devices.

In many instances these differences may have been related to another, that of a class difference in the ability to think ahead, to plan for future advantage, even at the cost of foregoing some immediate gain. This is seen particularly in relation to punitiveness; in general, middle-class mothers were more inclined to comfort or distract a distressed or tiresome child, or to prevent the situation arising, while working-class mothers were more inclined to punish or ignore the same kinds of behaviour. Comforting a child takes more time than ignoring him; distracting a furious child more than shouting at him; anticipating and preventing naughtiness more than smacking him when he is naughty. The mothers who comfort, distract and anticipate do so because, although it is more effort at the time, they believe they will save trouble in the future, that these methods, which take longer to apply, are worth it because they are more effective in clearing up the real cause of the trouble, and perhaps will go some way towards preventing it occurring in the future. These mothers seem to feel that distress uncomforted is not resolved, that little is gained by smacking a naughty child, and that in fact future difficulties may be aggravated by handling present ones like this. Being much concerned with the future they are prepared to put themselves out in the present. On the other hand the mothers who tend to ignore or punish their children seem to be acting on an impulse of the moment, taking the action which seems immediately appropriate. Many a mother will know the effort, mental as well as physical, that it takes to disengage herself from washing, cleaning, bed making, pastry making or whatever, cleaning or drying her hands and breaking into her concentration on the current task, to comfort or deal with a toddler in distress. To some mothers it is less effort to ignore the toddler, or quicker to give him a slap and hope that this will have the desired effect, while the possible long term effects are not considered. Since on the whole this long term planning, postponement of present ease for future gain, is more characteristic of the middle classes (in for instance, their willingness to live on a small income while training for a better job, to pay for what they think of as a better education and hence a better future for their children, and so on) it seems reasonable to suppose that this attitude may also affect the way they handle their children.

**QUESTIONS CONCERNING ONLY THE MOTHERS
OF THE DOWN'S SYNDROME CHILDREN**

Agencies of help

More working-class mothers were never visited by the various agencies. The figures, shown in Table 9.7, although not individually statistically significant, show a consistent trend.

TABLE 9.7
Agencies of Help and Social Class

	<i>Middle class (No. %)</i>	<i>Working class (No. %)</i>	<i>Level of significance (%)</i>
Those never visited by:			
Health Visitor, 4 years	42	55	
Mental Welfare Officer	26	50	
N.S.M.H.C.	74	95	
Other	58	85	
Hospital visits helpful, 4 years	64	18	1
Clinic visits helpful, 4 years	86	57	
G.P. helpful	41	68	
Had genetic advice from a doctor	26	55	
Would like a special clinic	37	65	
Special clinic wanted to avoid embarrassment	5	40	5

Not surprisingly perhaps, a third of the working-class mothers compared with only two middle-class mothers would have liked more visits than they were getting. Three working-class mothers were members of the N.S.M.H.C. compared with two-thirds of the middle-class mothers. Only one working-class mother found the Society's meetings helpful, compared with 58 per cent of the middle-class mothers (the majority of these last also found 'Parent's Voice', the Society's newsletter, helpful, but a few had benefited too from outings organized by the Society and from introductions to schools and to the Society's Trustee Scheme).

Of those whose children attended a hospital fewer working-class mothers found the visit helpful. The same trend was seen in connection with visits to the Infant Welfare Clinics, but slightly more working-class mothers found their family doctor helpful and more had discussed with a doctor the question of future children. The latter difference is not due to a preponderance of younger working-class mothers; of the mothers given genetic advice, three out of eleven working-class mothers and two out of five middle-class mothers were under 30 years old.

Slightly more working-class mothers would be glad of a special clinic for handicapped children, especially as an escape from the embarrassment of taking the child to the ordinary clinic.

So it seems that, with the exception of the family doctor, working-class mothers received less help from the various social agencies, the N.S.M.H.C., hospitals and clinics. This seems particularly unfortunate since on the whole the working-class mother is less likely to have the confidence to set about finding the help she needs or to have any idea how to do so. It seems that what is needed is a more vigorous and positive attitude on the part of the various agencies. Probably all parents of handicapped children need a sympathetic and interested approach, but where the parents are working-class people this need is even greater, since they are less likely to voice their worries or to ask questions if they do not understand what they have been told. Perhaps doctors and social workers need to be even more aware of this class difference, so that they may be ready to give more time and fuller explanations particularly to working-class parents, in a form of 'positive discrimination'.

Changing the child if this were possible

During discussion of TV documentaries on mentally handicapped children the programme on Nigel Hunt, which the majority of parents had seen, was discussed. At one point in the programme Nigel's father had said that he and his wife had never wished Nigel were other than a mongol child. The mothers were asked whether they agreed with this, or whether, if they had the power to change their child into a normal child, they would want to do so. The replies are shown in Table 9.8.

TABLE 9.8
Changing the Child

	Middle class (No. %)	Working class (No. %)
Would change	83	45
Would not	6	55
Don't know	11	-

Omitting the 'don't knows', these differences are significant at the 1 per cent level. There was no relationship between the age of the mother and whether or not she would want the child changed. Several mothers who would change the child said this would be for the child's own sake.

'Yes, I would, for his own sake, especially when he's older. It's a terribly long life to go through and never be able to go about with other children.'

'It's a terrible pity she isn't normal, when you think of all she's missing.' (Working class)

'For their own sakes you want them to be perfect.' (Middle class)

Some mothers, although they gave definite answers one way or the other, were at times uncertain.

(Would change). 'There are fleeting moments when I cuddle her and think, "you wouldn't do this if you were normal." But if she would go into the garden and just call out, "Mummy, there are some birds," it would be so marvellous. And she'll never be independent, and someone might illtreat her.' (Middle class)

(Would not change). 'I sometimes think it will be a problem when he grows up.' (Working class)

Many of those who did not want to change the child had come to value him as he was.

'Alan wouldn't be Alan if he wasn't a mongol.'

'I wouldn't want him any different. I like him as he is, I never wish he were normal. He's so defenceless and dependent.' (Working class)

It is often said that intelligent middle-class parents find it especially hard to accept a mentally handicapped child, since they tend to have high intellectual ambitions for their children; and that the average working-class family is a better one for such children to be born into, as they are here more easily accepted and loved. The replies to the question on changing the child gives some support to this view. It may be however that this difference between the social classes is related to the middle-class tendency, already discussed, to look ahead and take a long term view. It may be that the working-class mother's acceptance of her child, and her unwillingness to have him altered, is related essentially to the 'here and now' situation of a beloved small individual; while the middle-class mother may be more strongly influenced by thoughts of the future and of possible future difficulties both for the family and for the child himself.

Mother's communication

The mothers were rated on a three point scale as to how much they talked to the child during the interview and they were asked how much they tried to teach him to do, to sing and to say (teaching colours, numbers, alphabet and names were counted separately). Each of these replies was rated from none (0) to much (2). These points were totalled for each mother and constituted her 'communication score'. The total scores ranged from 2 to 14 (the higher the score, the more the mother communicated with the child).

with an average for the whole group of 7.7. The average for middle-class mothers was 8.4 (range 3-13) and for working-class mothers 7.0 (range 2-14).

In order to see whether more communication by the mother was associated with higher intelligence in the child, and vice versa, each mother's communication score was correlated with the mental age of her child at 4 years old, using Pearson's product moment correlation. The results are shown in Table 9.9.

TABLE 9.9
Correlations Between Mothers' Communication Scores and Children's Mental Ages
at 4 Years

	<i>r</i>	<i>n</i>	
Whole group	+0.18	39	not significant
Middle class	+0.64	19	significant at 1% level
Working class	-0.55	20	significant at 2% level

Over the whole group, there was no significant relationship between the amount of communication by the mother and the mental age of her child. Within the middle-class group there was a significant positive correlation between these two factors; within the working-class group there was a significant negative correlation.

Two further investigations were made, to see what was the effect of other small children in the family, and the age of the mother, on these correlations. No clear relationship was found between the presence or absence of other young children in the family and the mother's communication score. Middle-class mothers were rather less likely to be 'high communicators' if they had other young children aged 6-10, working-class mothers if they had other children under the age of 5, but in neither case was this significant. In view of this and the fact that numbers of young children were similar in the two groups, it seems that other young children did not have a major effect on the correlations. When the mother's age was considered it was found that younger mothers (38 and under at the child's birth) in both social classes were slightly but insignificantly more likely to communicate than were older mothers. There were in this sample slightly more younger mothers in the middle-class group—11 compared with 7 in the working-class group—but the difference is not significant; it seems unlikely that the mother's age had a major effect on the correlations.

If the correlations, between the mother's communication score and the child's mental age, had been positive over the whole group it would have seemed likely that extra stimulation given by a mother brought about improvement in a child's ability. However, in the working-class group the

correlation is negative, and one would have to say that extra stimulation given by these mothers brought about a reduction in the child's ability; such an explanation is hardly feasible. It is suggested that instead of looking at the effect the mother's efforts may have on the child's condition, we might examine the effect the child's condition may have on the two groups of mothers. It then seems that the middle-class mother may be more influenced by the amount of feedback she gets from her child; that where she has a comparatively bright, responsive child, she is the more ready to exert herself, to make an effort to teach him where she can see such efforts bearing at least some fruit; but where she has a slow, lethargic, withdrawn child who does not respond to her overtures, she gives up the effort to teach him. Such an explanation is consistent with the positive correlation between communication score and mental age in the middle-class group. In the working-class, the situation is rather different. Here it seems that the mother's efforts are called forth, not so much by the child's responsiveness as by his need; that is, if he is fairly alert, getting on fairly well, she is content to leave him to do so at his own pace. If however she sees that he is way behind in his achievements she feels the urgent need for stimulation for him, and makes strenuous efforts to bring him on. Another possible factor is suggested from the writer's personal impression of the mothers. Whereas the middle-class mothers seemed consistently to depend on feedback from the child, with the working-class mothers, whether or not they exerted themselves to teach the child seemed to depend more on luck, on the individual mother's personality. Some mothers would simply accept the child as he was, either high or low grade, without trying to do very much about him; others were not to be deterred by any disadvantage or difficulty, they *would* teach him, come what might; and this seemed to depend more on the mother's own personality than on the kind of child she had. These two hypotheses would be consistent with the lower, negative correlation between communication and mental age in the working-class group; whether they are valid hypotheses would have to be decided by a larger scale and more detailed investigation.

SOCIAL CLASS AND THE MOTHERS OF DOWN'S SYNDROME CHILDREN

In the whole group of mothers the three major differences between the social classes were, that middle-class mothers were first, less punitive and more permissive; second, that they were more closely involved with their children's behaviour; and third, that they were more likely to be concerned with the future effect of their actions than were the working-class mothers. When we consider the mothers of Down's Syndrome children only, in all but one area, that of the mothers going out to work, discussed on page 104, the

differences were the same or in the same direction as in the control group. In some cases the trends were similar but less pronounced—in, for example, comforting or punishing an upset child, in soothing or leaving a crying child, and in starting toilet training and success with it at 4; in others the trends were similar but more pronounced—in, for example, early feeding and in where the children slept; but there is little consistency. Because of this, and because of the small numbers involved, it is not possible to say that these were significant trends. Leaving aside the special differences found between the social classes on items applicable only to them (on agencies of help, communication and so on) the general conclusion to be drawn from this study is that mothers with Down's Syndrome children tend to be influenced by the social class to which they belong in much the same way as are mothers of normal children. Perhaps this is not surprising; but if parents were involved in 'early intervention' or behaviour modification programmes it would be interesting to see how far either group moved away from the pattern of attitudes and behaviour characteristic of their social class.

10

15 Months to 4 Years. A Longitudinal Comparison

Thirty-six mothers of Down's Syndrome and 41 mothers of controls were interviewed at both ages when their children were 15 months and 4 years old. It was possible to compare the children's abilities and behaviour, and the mothers' behaviour and attitudes, at the two ages; and to explore what effect, if any, the mothers' behaviour and attitudes at 15 months might have had on the children's behaviour at 4 years.

In the tables that follow there are many variations in the total numbers involved. For instance, in the 77 families seen when the child was 4 years old, there were 6 (5 Down's Syndrome, 1 control) in which one parent was missing (1 mother, 5 fathers) so the number responding to questions on parental agreement and so on is reduced. However one father of a Down's Syndrome child had died very recently and the mother was able to answer many questions which involved him (such as those concerning father's participation) and the motherless Down's Syndrome child had a well established substitute mother who answered questions about her handling of him (but not about going out with the father etc). The numbers involved have therefore been specified in each of the tables.

THE SITUATION FOR THE MOTHERS

Mothers who were or were not working at 15 months tended to be in the same situation at 4 years. One-third of those working earlier had stopped, and a quarter of those not working earlier had taken up work during the three years' interval.

Similarly more mothers who went out in the evenings with their husbands fairly often, and who felt they went out enough, at 15 months, were in a similar situation at 4.

TABLE 10.1
The Mothers' Situations

	Combined group (No. %)	Level of significance (%)
Working at 15 months (N = 25): similar at 4 years	68	0.1
Not working at 15 months (N = 51): similar at 4 years	76	0.1
Evening outings occasionally + at 15 months (N = 43): similar at 4 years	74	0.1
Evening outings seldom or never at 15 months (N = 28): similar at 4 years	71	0.1
Contented with frequency of outings at 15 months (N = 42): similar at 4 years	76	5
Not contented with frequency of outings at 15 months (N = 29): similar at 4 years	48	

THE ABILITIES AND ACHIEVEMENTS OF THE CHILDREN

Food and feeding

Scores for each of the Down's Syndrome children at 15 months on: age of starting solids, enjoying food, and ability to feed himself with fingers, cup and spoon, were compared with each child's score at 4 years on the food eaten (ordinary, minced, and so on) and ability to feed himself. No significant associations were found, though there were slight tendencies for children who could feed themselves to some extent at 15 months with fingers or a cup to be more likely to feed themselves well at 4 years. Similar comparisons could not be made on the control children since virtually all of them could feed themselves entirely by 4 years.

Dressing

In both groups those children who gave at least some help with dressing at 15 months were more likely to dress themselves completely or with only a little help at 4 years old, and this was significant for the combined groups.

In order to see whether this association could be ascribed simply to intelligence—i.e. that good dressers at each age were the more intelligent children in each case—a comparison was made between intelligence and dressing ability at each age, for each group of children and for the two groups combined. At 15 months the relationship was positive for both groups—that is, the more intelligent children were better dressers—and for the combined

TABLE 10.2
Dressing Ability at 15 Months and 4 Years

	Combined group (No. %)	Level of significance (%)
Good dressers at 15 months (N = 37); similar at 4 years	62	0.1
Poor dressers at 15 months (N = 38); similar at 4 years	76	0.1
Good dressers at 15 months (N = 37); above average IQ at 15 months	71	5
Poor dressers at 15 months (N = 38); above average IQ at 15 months	42	
<i>Down's Syndrome</i>		
Good dressers at 4 years (N = 8); above average IQ at 4 years	88	
Poor dressers at 4 years (N = 31); above average IQ at 4 years	39	
<i>Controls</i>		
Good dressers at 4 years (N = 25); above average IQ at 4 years	60	
Poor dressers at 4 years (N = 16); above average IQ at 4 years	63	

groups was significant at the 5 per cent level. At 4 years the difference was in the expected direction for the Down's Syndrome children but not for the controls, in that a higher proportion of poor dressers were also above average IQ. (This is related to the fact that average intelligence was higher in the middle class group, but fewer of these children were independent for dressing. See page 106.) So it seems that, especially in the control children, the positive association in dressing ability at the two ages was to some extent independent of intelligence.

Toilet training

How much the potty was used at 15 months, when toilet training was begun (before or after 12 months) and the mother's attitude to it were related to wetting and dirtying pants and wetting the bed at 4 years. (Again these scores are for the Down's Syndrome children only, as only 5 controls ever wet or dirtied their pants and only 7 ever wet the bed at 4.)

More children in each case who were using the pot at least occasionally at 15 months were clean and dry at 4; the differences were nearly significant for dry and were significant at the 5 per cent level for clean. No relationship was found between early pottng progress and bed wetting.

It was thought that the relationship between being clean and dry at the two ages in the Down's Syndrome group might be due to the common

TABLE 10.3
Toilet Training, 15 Months and 4 Years

	Down's Syndrome (No. %)	Level of significance (%)
Used pot occasionally +, 15 months (N = 18); seldom wet, 4 years	67	
Never used pot, 15 months (N = 18); seldom wet, 4 years	39	
Used pot occasionally +, 15 months (N = 18); clean at 4 years	83	5
Never used pot, 15 months (N = 18); clean at 4 years	50	
Training started before 12 months (N = 18); dry at 4 years	56	5
Training started after 12 months (N = 18); dry at 4 years	22	
Training started before 12 months (N = 18); clean at 4 years	83	5
Training started after 12 months (N = 18); clean at 4 years	50	
Mother concerned, 15 months (N = 19); children dry at 4 years	53	
Mother unconcerned, 15 months (N = 17); children dry at 4 years	24	
Mother concerned, 15 months (N = 19); children clean at 4 years	84	5
Mother unconcerned, 15 months (N = 17); children clean at 4 years	35	
Training started before 12 months (N = 18); children easy	33	1
Training started after 12 months (N = 18); children easy	83	
Mother concerned, 15 months (N = 19); children easy	37	1
Mother unconcerned, 15 months (N = 17); children easy	82	

factor of intelligence. There was no significant relationship between intelligence and being clean and dry at 15 months, but the relationship was significant at the 1 per cent level for both clean and dry at 4. At 15 months the mean mental age of the Down's Syndrome children was about 9 months, and at 4 years about 22 months; so in order to see whether the increased relationship between toilet training and mental age was associated with increase in mental age, the association between toilet training scores and mental age for the control children at 15 months was examined. No relationship was found. Since the mean mental age of the controls at that time was just over 15 months it may be that the extra 7 months of mental age (to 22 months for the Down's Syndrome children at 4 years) were crucial in producing the relationship between toilet training and mental age; or it may be that the relationship does not exist in children of normal intelligence, although it does in this group of Down's Syndrome children.

The age at which toilet training was begun was significantly associated with being both clean and dry at 4 years (but not with bed wetting); children who were started on the pot before 12 months were more likely to be clean and dry than were those who were started later.

It seemed possible that the more retarded children, if their mothers had recognized their limitations, might have been started later on the pot, so the association between the time of starting training and success at 4 years old might be due to differences in intelligence. However there was not a significant association between the time of training and mental age at 15 months. It seems that, in this group of Down's Syndrome children at least, an early start to toilet training did lead to better results in the day time.

Where the mother was rated as concerned about toilet training at 15 months, more children were clean and dry at 4 years than were those whose mothers were rated as unconcerned; the difference was significant at the 1 per cent level for clean and not quite significant at the 5 per cent level for dry. Where bed wetting was concerned the differences were in the same direction but did not approach significance.

Although the number of controls who were still not clean and dry by 4 were too few—five—to permit a detailed analysis in their case, it may be worth noting that at 15 months 4 of these never used the pot for wetting and 3 never for bowel movements; 3 were started on toilet training late, and all 5 mothers were rated as unconcerned. These are in every case higher than the proportions found in those controls who were reliably trained by 4. The figures are far too small to be significant, but it seems that such indications that exist in the control group support those found in the Down's Syndrome group, namely that children who were started early and made good progress in toilet training and whose mothers were concerned about it were more reliably trained at 4 years old than those children who were started later and made poor progress and whose mothers were unconcerned about training.

The Newsoms found no significant difference in the time of starting training, early potty progress, and the mother's attitudes and aspirations at 12 months, between children with and without residual toilet training problems at 4 (Newson, 1968, pages 339-345). In comparing time of starting training and mother's attitudes the tendencies they found were in the same direction as in the present study—that is, slightly more children who were started late on the pot and whose mothers were rated as unconcerned at 12 months were still having toileting problems at 4. The tendency for the relationship with early potty progress was slighter and in the opposite direction—slightly more children who were 'often successful' at 12 months were still having toileting problems at 4.

On the whole then the tendencies in the two groups of normal children, though in the same direction, were much slighter than for the Down's Syndrome children. It seems that a mother has a much better chance of dictating her wishes over toileting to a child with Down's Syndrome, and of his accepting this, than she has with a normal child. This suggests two things; first, that a Down's Syndrome child may have fewer and less clear-cut ideas

and feelings of his own regarding toilet training than has a normal child, so that he may less actively resist the training process; and secondly, that if a mother is determined and energetic enough about training a child with Down's Syndrome she is likely to achieve a good measure of success. Lastly, these results on all three groups, Down's Syndrome children, controls and the Newsoms' sample rather go against the generally accepted idea that early toilet training efforts are likely to lead to toilet training troubles later on (Spock, 1955, pages 177-187; Kelly, 1960) though the Newsoms say that they came across many individual cases where this had apparently happened (op. cit., page 344).

Another argument often put forward in support of an undemanding toilet training regime is the suggestion that severe or rigid toilet training may lead to personality difficulties, and particularly to negativism, in the future (Spock op. cit., pages 179-180). To investigate this, the time of starting training and the mother's attitude to it at 15 months were related to ratings of how easy the child was to manage and to temper tantrums at 4. These comparisons were made on both Down's Syndrome and control children. First however, since 'easy to manage' could mean quiet, slow, timid children, and perhaps girls rather than boys, the ratings 'easy to manage' and 'problem' were investigated in relation to sex, intelligence and to the rating of aggressiveness. Twenty-three Down's Syndrome children and 21 controls were rated as 'easy to manage', 5 and 6 respectively as 'a problem'. (The remainder were rated as 'average'.)

SEX

The sexes were evenly distributed in both the 'easy' group—21 boys and 23 girls—and in the 'problem' group—5 boys and 6 girls.

INTELLIGENCE

In both groups the majority of the 'easy' children (64 per cent of the combined groups) were above the average for their group in intelligence; the 'problems' were evenly split in the Down's Syndrome children and were all below the average in the controls. The differences are not quite significant at the 5 per cent level.

AGGRESSION

In the 'easy' category (44 children) 4 children in each of the Down's Syndrome and control groups were rated as passive and 3 as aggressive. None of the problem children were rated as passive, and 2 Down's Syndrome

and 4 control 'problem' children were rated as aggressive. In the 'average-to-manage' group (26 children) 5 were rated as passive and 8 as aggressive. So the 'easy' group were somewhat low on aggressive scorers while the 'problem' children were low on passive and high on aggressive scorers.

So as regards intelligence and aggressiveness the 'easy-to-manage' children seem to have been not very different from the average group; but the 'problem' children tended to be more aggressive and rather less intelligent than the average.

With this established, we may now turn to the relationships between the mother's attitude to, and time of starting, training, and the child's manageability and temper tantrums at 4. For the Down's Syndrome children both the time of starting training and the mother's attitudes were negatively associated with whether or not the child was easy to manage—that is, more children who were started on the pot late, and more children whose mothers were rated as unconcerned with toilet training at 15 months, were said to be easy to manage at 4, both differences significant at the 1 per cent level. Neither of the associations with tantrums, of time of starting training nor of mother's attitude, was significant. For the controls, none of the associations was significant. So where the effect of toilet training on future personality is concerned, the statements of the baby books are to some extent upheld in the case of the Down's Syndrome children but not in the case of the controls. It may be that the situation is more complicated and subtle for the normal children. Caldwell (1964) in a comprehensive review of studies of infant care practices and their effect on future development, found that the timing and type of infant care practices, including toilet training, seemed to have no significant association with psychological development, and she comments, 'The interpersonal context in which training occurs appears to be more influential than either timing of the training or methods used.' Nevertheless, it does seem that the mother of a Down's Syndrome child can to some extent make a choice between getting, by her own efforts at toilet training, either a clean child or an easily manageable child at 4 years old.

BEHAVIOUR OF THE CHILDREN

Sucking

Slightly more children in both groups who at 15 months never sucked anything (thumbs, cloths etc.) showed another habit, mostly sucking, rarely at 4 years old, but the figures do not quite reach significance.

However the tendency is in accordance with Caldwell's (1964) finding that, 'studies concerned with oral gratification and oral activities provide little support for the hypothesis that sustained gratification leads to drive

TABLE 10.4
Behaviour Patterns, 15 Months and 4 Years

	Combined group (No. %)	Level of significance (%)
Sucked rarely, 15 months (N = 24); sucked rarely at 4 years	50	
Sucked occasionally +, 15 months (N = 53); sucked rarely at 4 years	34	
Woke seldom, 15 months (N = 66); woke often, 4 years	20	
Woke occasionally +, 15 months (N = 10); woke often, 4 years	40	
Tempers occasionally +, 15 months (N = 43); occasionally +, 4 years	81	
Tempers seldom, 15 months (N = 34); occasionally +, 4 years	38	0.1

satiation' (page 80). In the present study there were no differences in the habit at 4 years old between those children whose mothers were or were not permissive about the habit at 15 months.

Night waking

Slightly more children in both groups who woke often or occasionally at 15 months also woke often at 4, compared with those waking seldom at 15 months. Again the figures do not reach significance.

Temper tantrums

In each group significantly more children who had temper tantrums at least occasionally at 15 months were similarly rated at 4 years old, compared with those who seldom had tantrums at 15 months. The figures for the combined groups are shown in Table 10.4. So it seems that a child's tendency to tantrums (or the mother's report of it) is likely to be consistent up to 4 years old.

THE MOTHERS' BEHAVIOUR AT 15 MONTHS AND THE CHILDREN'S BEHAVIOUR AT 4 YEARS

Night waking

Most of the children slept well at both ages (over 75 per cent of the Down's Syndrome, over 60 per cent of the control children). Of those who did wake, it appeared that unsympathetic treatment at 15 months was more effective

than permissive treatment in bringing about uninterrupted sleep at 4 years. Of the 7 children who at 15 months were unsympathetically treated for waking, at 4 years 6 never woke, and none woke often; of the 9 who at 15 months were taken into the parents' bed when they woke, at 4 years 2 never woke and 6 did so often. Neither was it the case that children were taken into the parents' bed at 15 months because they woke often; only one was waking often at that time and the other 8 seldom or never. Six of the 18 children who woke often at 4 years were those who had been taken into the parents' bed at 15 months. So it seems that taking the child into the parents' bed tended to produce more wakefulness at 4, whereas sterner measures tended to discourage it—not perhaps a very palatable finding for a permissive child psychologist (such as the writer).

Tempers and their treatment

In both groups unsympathetic treatment of tantrums at 15 months was associated with a slight tendency to more frequent tempers at 4, though the differences were not significant.

TABLE 10.5
Parent's Behaviour at 15 Months, Child's Behaviour at 4 Years

	Combined group (No. %)	Level of significance (%)
Tempers treated unsympathetically, 15 months (N = 34); tempers often at 4 years	26	
Tempers treated kindly, 15 months (N = 19); tempers often at 4 years	5	
Constant supervision, 15 months (N = 13); much mischief at 4 years		
Little supervision, 15 months (N = 35); much mischief at 4 years	8 40	5
Father highly participant, 15 months (N = 25); highly participant at 4 years		
Father not very participant, 15 months (N = 19); highly participant at 4 years	88 26	0.1
Parents agree or father less strict, 15 months (N = 52); child easy at 4 years		
Father more strict, 15 months (N = 19); child easy at 4 years	58 37	
Parents agree or father less strict, 15 months (N = 52); child a problem at 4 years		
Father more strict, 15 months (N = 19); child a problem at 4 years	11 24	

Close supervision at 15 months and mischief at 4

There was in both groups a tendency for more children who were closely supervised at 15 months to get into very little mischief at 4, while more of those who had little supervision at 15 months got into a great deal of mischief at 4. Since one might expect children to be fairly consistent in their mischievousness from one age to another (and indeed there is a slight but insignificant tendency for children who were not naughty at 15 months to show less mischievousness at 4) the direction of the association is unexpected. It suggests that children who are closely supervised and presumably stopped from wrong-doing, learn that mischief is not worth while and give it up; whereas those who have a free rein from an early age go from strength to strength, becoming more mischievous as mischief goes unchecked.

The mothers' religious beliefs and disciplinary methods

Forty-four mothers were practising Christians, and 32 non-practising (including 2 who did not have any religious beliefs). These two groups were compared for: believing in smacking, smacking at 15 months and smacking at 4 years. No significant differences were found, though there was a slight but consistent tendency for practising Christians to smack less, and to believe in smacking less, than did the non-practising.

There were 10 Roman Catholic mothers, whose answers were evenly split between smacking and non-smacking.

ROLE OF THE FATHERS

More fathers in both groups who took a large part in caring for their children at 15 months also took a large part in caring for them at 4, compared with those fathers who did little or nothing for their children at 15 months.

On the whole fathers had become more participant as their children grew older. Twenty-eight were rated as more participant when their children were 4 years old than they had been when the children were 15 months old (including 5 who earlier had been rated as 'non-participant' and were rated as 'highly participant' when their children were 4). Five fathers were rated as less participant on the second occasion. Many fathers do play a large part in caring for their very young children,* but some, who find

* 'At a time when he has more money in his pocket, and more leisure on which to spend it, than ever before, the head of the household chooses to sit at his own fireside, a baby on his knee and a feeding bottle in his hand: the modern father's place is in the home.' Newson, J. and E., 1963, page 147.

infants rather daunting, come into their own when the children are older; by the time the children in the present survey were 4 years old only 6 of the 72 fathers were said to have little to do with them.

There was no difference in the proportions of 'easy' or 'problem' children of participant or non-participant fathers. In addition, of the 6 children who were by 4 years without one or other parent (5 fathers, 1 mother) 4 were said to be easy and none was a problem, so it seems that in this study fathers did not play a major part in the development of manageable or problem behaviours in their children, at least as seen by their wives.

Where parents agreed about discipline, or the father was said to be less strict than the mother, there tended to be proportionately more 'easy' and fewer 'problem' children, compared with those whose fathers were said to be stricter than the mother, though the differences are not quite significant. When the father is said to be more strict this implies that the mother is less strict than he is, and this in turn may imply that the mother is less confident of her own ability to deal with her children. (In fact of those mothers who said that they were quite happy about the way they handled their children, 23 per cent said the father was stricter, compared with 39 per cent of those who had some doubts about how they handled the children.) It may be that this lack of confidence makes it more difficult for the mother to deal adequately with the children's behaviour, and this may result in more difficult and fewer easy-to-manage children.

SUMMARY AND DISCUSSION

So over the period of 3 years between the two studies, a good deal of consistency has been found in the way of life of the parents. On the whole the same mothers were working, the same fathers taking an active part in caring for their children, the same parents going out much or little in the evening, and displaying the same degree of contentment with their lot. Some of the children's abilities too were consistent, especially in dressing and in day-time toilet training, while in their behaviour tempers were consistent from one age level to another.

Perhaps the most interesting findings concern the effect of the mother's actions at 15 months on the child's behaviour at 4. Early and relatively severe toilet training resulted in cleaner children at 4, and though Down's Syndrome children thus trained were more difficult to manage at 4 no such effect was noticed in the controls. Although few of the 4-year-olds woke at night, it seemed that they were less likely to do so if their waking had been treated unsympathetically than if they had been treated comfortingly for waking at 15 months. Children who were closely supervised at 15 months (presumably because they were mischievous) were likely to be less mis-

chievous at 4 than those who had been left to their own devices. In general these findings do not support the teachings of the psychoanalysts but rather those of the behaviour therapists—training trains children, and does not necessarily damage them (at least up to 4 years old), aversive treatment decreases an undesirable behaviour and positive treatment reinforces it, and so on. The group of subjects in the present study was too small to draw firm conclusions from these findings but a larger scale study of child rearing practices and child behaviours at different ages might provide more hard facts on which to base advice on child rearing.

11

Conclusion

THE EFFECT ON THE FAMILY

'No simple answer can be given to the question: what is it like to have a mentally subnormal child, and what should one do about it?' The conclusion reached by Tizard and Grad, in 1961 (page 120) is still applicable today, even where the group of children under consideration is as homogeneous as far as handicap is concerned as are those with Down's Syndrome. Families differ in composition and outlook, and in the problems they already had before the child was born, and this in turn affects how they deal with the new problems that he brings. In the present study we have been concerned mainly to discover general trends, to discover what the majority of the babies did, how the majority of the mothers reacted or how they felt about their situation. But whenever a trend was found there were always some who were not included in it, and a most important if rather obvious lesson that we learnt was that, with any individual mother, we should never think we knew how she felt or thought, or what her wishes in any particular situation would be. Most mothers are glad enough for their children to attend school and to gain for themselves a few hours peace thereby; *this* mother may not feel like that and may resent the hasty assumption that she does. Most mothers want advice and help in managing their babies but occasionally a mother may be met with who prefers to be left alone. Similarly the vast majority of children with Down's Syndrome are severely mentally retarded, but a small number reach higher levels of achievement; a mother's hope that her child will be one of the higher grade children should be respected, and no child should be assumed to be in any particular educational category, however convenient this might be administratively, until he has been carefully assessed. It is of great importance that surveys like the present one which attempt to describe general trends should not lead professional workers to overlook individual differences; no individual should be taken for granted.

Nevertheless some general conclusions are possible, and of these, perhaps the most striking is that the difficulties encountered by these families were not as numerous or as severe as we had expected. In many aspects of day-to-day living—for example, sleeping, crying, tantrums, and the availability of nursery schooling—the families of the Down's Syndrome children were even at a slight advantage compared with the families of the normal children. In other respects there was little difference between the groups; for example in the health of the mothers, holidays, in the manageability and aggressiveness of the children, participation of the fathers, amount of washing the mothers had to do. In all these areas the difficulties were those encountered by families with a small child of any sort, and those whose baby had Down's Syndrome were not at a particular disadvantage.

There were of course some problems. Feeding, especially when the child was very young, was a serious problem to some mothers of Down's Syndrome babies and an increased anxiety to many. The Down's Syndrome children were well behind the normal children in their ability to dress themselves, and in toilet training, and were naughtier at a time when the normal children were becoming more amenable; they had more health problems, and their mothers were more restricted in their outings and so perhaps in their social contacts (though this may not be entirely ascribable to the child's condition but may have been related partly to the mother's age).

These then were the main problems of the families in the present survey. With the exception of feeding, none of these were thought by the mothers to be serious problems. Perhaps it should be said at once that this rather rosy picture applies, so far as we know, only until the children are 4 years old, and that it is quite possible that as they get older and as the divergence between the normal child and the child with Down's Syndrome becomes yet more marked, the difficulties may become greater. The mothers themselves were aware of this possibility; their worries were not for the present but for the future. For the child they foresaw a life of limitations, dependency, second class education and employment, the impossibility of marriage; for themselves perpetual responsibility, anxiety, perhaps humiliation, above all perhaps the worry of what would happen to the child when they themselves were no longer able to look after him. The dread of all this in the future constituted the main source of stress for the family of the young child with Down's Syndrome. Perhaps it is worth knowing that, as a rule, other major problems are few. If, as we believe, the child with Down's Syndrome is helped by being allowed to grow up in his own family, it may help the family in their turn to know that they are unlikely to suffer damage from him, at any rate while he is young.

MEDICAL SERVICES

All the parents in the present study had had a good deal of contact with the medical services, and many were unhappy about their experiences, especially where hospitals were concerned. Since the visits to hospital were so particularly unsatisfactory to nearly two-thirds of the mothers, we think it worth while to consider why this should be so and what could be done about it. First we think that the purpose of these visits should be more carefully considered. In few cases was there any medical necessity for the child to visit the hospital, and there was very little medically that the doctor could do for him when he got there. We believe that this situation increases the likelihood of feelings of frustration on the part of both doctor and parent, who would in each case feel more satisfaction if something concrete could be done for the child. This being so, it might be better to reduce the number of visits that each child has to make, at the same time increasing the length of each visit to allow time for proper discussion of the child and of the mother's problems; for the doctor to probe for problems if the mother does not ask questions, and, wherever possible, to give advice. We believe that such a system of reduced frequency and increased duration of the visits would lessen the mothers' feelings of frustration, and enable the true purpose of the visits—that of counselling and supporting the mothers of children whose condition cannot at present be medically cured or alleviated—to be more adequately met.

Much of what has been said about hospital doctors applies also to the family doctors, with the addition, which perhaps cannot be repeated too often, that a sympathetic and affectionate interest in the child can do a great deal for the mother, even in the absence of specialized knowledge or treatment. The situation with the Infant Welfare Clinics is a little different, and it is interesting that more mothers were satisfied with the services of these than of the other medical services. The question arises as to whether there should be special clinics for mentally handicapped children, and probably the suggestion of Tizard and Grad (1961, page 123) that these should be available, staffed by the same staff as the ordinary clinics and supplemented by specialists, is the best one; but it does not altogether get over the difficulty that such special clinics would tend to isolate the parents of the mentally handicapped, and their children, from other parents and children. (As one mother of a Down's Syndrome child said, 'Once you were put in special places that's where you'd stay.') Perhaps the mother of the mentally handicapped child could be encouraged to go to the ordinary clinic in the ordinary way and to go to the special clinic if she had special problems to discuss or disliked taking her child to the ordinary clinic; or the special clinic might be substituted routinely, from time to time, so that specialist staff could meet all the mothers and not only those who themselves undertook a visit to the special clinic.

THE SOCIAL AND EDUCATIONAL SERVICES

One of the encouraging aspects of this survey was the goodwill the mothers met generally, which seems to reflect a considerable shift in the climate of public opinion towards a greater acknowledgement and acceptance of the mentally handicapped. We believe that this change has been brought about, first, by the work of such people as O'Connor and Tizard (1954, 1956), Tizard and Grad (1961) and Clarke and Clarke (1958) in drawing attention to the situation of retarded people and to how they can be helped; and secondly, to the greatly improved range of services available, and in particular to the special schools and workshops which have perhaps done more than anything else to give the mentally handicapped person a positive and productive position in the community. In the present study the provision of schooling was felt to have done a great deal in alleviating the problems of the mothers, but perhaps more could be done. There could be more contacts between the schools and the homes, especially before the child was old enough to attend school himself, so that his parents could see the provision that was made, the kind of care, stimulation and training that their child would get. Some mothers may be dismayed by such a visit, thinking that their baby could never be 'that bad' compared with the children they saw, but many mothers would be helped by seeing the special school early on. Similarly some contact with a senior training centre and visits to sheltered workshops would enable mothers to see the continuing prospects for their children. This is the more important since the outlook for the long term future is often for the parents the greatest worry of all.

Parent groups, such as those organized by the National Society for Mentally Handicapped Children, might be expected to play a major part in helping parents to overcome their difficulties, and it was disappointing to find that this was not so among the majority of mothers in this study. This may be due partly to disinclination on the mothers' part to involve themselves too deeply in mental handicap; Roith (1963) also found only just over half the parents were in favour of parents' meetings. But a more vigorous policy on the part of the N.S.M.H.C., with branch members encouraged to call on mothers of mentally handicapped babies with offers of information, friendship, and fellow feeling, might be helpful. Local branches would need to be notified as new cases were identified, and this might be done through co-operation with the general practitioners. In turn the Society might supply the general practitioners with leaflets containing details of the Society's services and functions, so alerting the doctors to the Society's existence and increasing the chances that every mother of a mentally handicapped child was at least offered contact with the Society as soon as she was aware of the child's condition. In this way she could learn in the early stages of such help as the Society was able to give, and make contact, if she wished, with other

mothers of handicapped children, and this could play a major part in helping the parents over their initial feelings of bewilderment and isolation.

HEALTH VISITORS AND EARLY INTERVENTION

In any condition discoverable at birth it is natural to look to the Health Visitors for much of the necessary help for the mothers, since the Health Visitors are routinely in contact with all mothers of new babies. In one simple way they could perform a very useful function, in conveying to the mothers some of the information they so badly need but so often fail to get. It seems obvious that specialist knowledge and techniques and a whole range of special services will be of little use unless those who need them know of their existence. One solution to this problem might lie in a series of books and pamphlets, setting out clearly the information the mothers require, ranging from advice on the care and management of the children to details of special schools, temporary care facilities, the N.S.M.H.C., and so on. Some of these pamphlets already exist; some still need to be written. Some should be produced by each local authority and would need to be kept up to date—mothers do not want to know what *may* be available, they want to know what *is* available in their area, and it would be pointless and cruel to describe facilities, such as for instance special school nursery classes, if no such thing existed in the area. The health visitors then, knowing which mothers had handicapped children, could call on the mothers with the pamphlets. In some cases she could go through these with the mothers and discuss them, and how the various points applied to the mother's own child. The timing of the health visitor's approach might pose some problems. As we have seen, most mothers in this study would have liked this sort of information as early as possible after they knew that the child was handicapped, and here the family doctor's co-operation, in telling the health visitors when the mothers have been told of the diagnosis, would be invaluable. If it was true that in the present study the interest and support that the mothers felt they had received had helped them to cope with their problems, then for future mothers an intensified programme of visits from the health visitor, especially if she were armed with the sort of information already described, might do much to help other mothers.

Ideally, however, more is needed. Valuable as informative literature might be, of much greater value might be an early intervention service. Studies along these lines have been pioneered by de Coriat *et al.* (1967) and in this country by Brinkworth (1971) and on a larger scale by Ludlow (personal communication). The studies have differed somewhat from each other in their approach, but all have shown, despite certain methodological drawbacks, considerable developmental advantage in the children whose mothers

were involved over those whose mothers were not involved in the early intervention programmes. In the service envisaged here, each mother would be contacted and visited as soon as it became apparent that her child was retarded. The person making the visit would be familiar with child development, with mental retardation and the principles of behaviour modification, and with the mental retardation services available in the area. The child would be carefully assessed, and the mother would be given an outline of the pattern that her baby's development was likely to show; of the major health problems he might encounter and how to cope with them; of ways to stimulate him to make the most of his abilities and of the best ways of handling him so as to minimize the possibility of behaviour problems; how to teach him self-help skills such as washing, dressing, and feeding; how to go about toilet training him; how to teach him to talk and to help him to mix with other children. Most valuably this service would be combined, as the children grew older, with provision of a mixed play group for normal and retarded children with the parents in attendance; this would not only continue to teach the mothers how to help their retarded children but also allow the mothers to have a chance to come in contact, with their children, with other friendly interested people and learn, in a favourable situation, how to face them and deal with their reactions. Mothers of normal children too might benefit from a greater ease and familiarity with handicap, and might learn to admire the abilities, achievements and qualities of the retarded and of their parents.

A programme of this sort would not cure the children or do away with all the parents' distress, but by removing some of the major doubts and uncertainties, by letting the parents know of the sources of help available to them, and above all by showing them how they themselves can help their children to make progress, both the children and their parents would benefit. And if in the future Down's Syndrome were to become a condition only to be read about in the medical history book and never encountered in real life, the programme would be equally applicable and equally helpful to families of children suffering from other forms of mental retardation.

Appendix I

STATISTICAL METHODS USED

Developmental study

Curves of scores

We wished to test the hypothesis that the mental and motor growth curves of different groups of children were the same. Tests were given at seven different ages, but not all the children were available at every age; in fact only 22 children with Down's Syndrome and 27 control children had complete sets of scores. Rather than reject a large part of the data we decided to fit least square regression curves, using all scores as independent points. It was appreciated that there would probably be some serial correlation present, and that, although the regression coefficients would be unbiased their estimated variances would probably slightly underestimate the true variance.

To avoid having to test whether higher order regression terms were significant the curves to be used were chosen before the analysis by examining plots of the mean scores at each test against chronological age. In the case of the DIQ's and DMQ's a quadratic, and in the case of the children with Down's Syndrome mental and motor ages a linear curve appeared the most suitable.

DIQ's and DMQ's. Chow's method of comparing regression equations

Since the variance of the scores was not stable, the transformation $\log e(c-y)^*$ was used. The curve $Y = \beta_0 + \beta_1 x + \beta_2 x^2 + e$ was fitted to the

* where $c = 3$ and $y =$ the sigma score.

data obtained for DIQ's and DMQ's for children with Down's Syndrome and controls, each of these groups being divided into boys and girls, and into the children of non-manual and of manual workers. The Down's Syndrome group was also divided into those brought up at home and those boarded-out in foster homes and institutions. For each group a set of regression coefficients β and the residual error σ were estimated. We wished to test the hypothesis $H_0: \beta_a = \beta_b = \beta^*$ for each pair of curves. This was done by computing:

$$F = \frac{Q_3/k}{(Q_2/n_a + n_b - 2k)}$$

with $(k, n_a + n_b - 2k)$ degrees of freedom.

where k = no. of coefficients

n_a = no. of scores in group A

n_b = no. of scores in group B

$Q_1 = S^2 (n_a + n_b - k)$

$Q_2 = S_a^2 (n_a - k) + S_b^2 (n_b - k)$

$Q_3 = Q_1 - Q_2$

S = estimate of σ (total group)

S_a = estimate of σ (group A)

S_b = estimate of σ (group B)

(See Johnson, 1963)

Mental and motor ages of Down's Syndrome children—linear regression

The straight lines were compared by estimating the standard error of the differences of the slopes and performing a t -test. As the standard errors may have been underestimated the t -values may have been slightly inflated. However at most 3 per cent of the off-diagonal terms of the covariance matrix was non-zero and even these values were expected to be small. It was therefore decided that a cautious interpretation of the results was more appropriate than lengthy calculations to estimate the bias of the variance of the coefficients.

* where β_a is the vector of regression coefficients of one sub-group, and β_b is the vector of regression coefficients of the other sub-group, and β is the vector of regression coefficients of the whole group.

Significance of the difference between single means

Since the distributions of the scores were not normal, and since the numbers involved were rather small, a non-parametric test, the Mann-Whitney U Test, was used, with the following formula:

$$U = \frac{n_1 \times n_2 + n_1 \times (n_1 + 1) - R_1}{2}$$

where n_1 = number of cases in the smaller group

n_2 = number of cases in the larger group

R_1 = sum of the ranks assigned to the group which is called n_1 .

Family study

The significance of the differences between percentages has been calculated throughout this part of the study using nomographs. These were originally published by Zubin and have been recalculated and adapted by Oppenheim (1966). Oppenheim warns that, using the nomographs, 'a given difference may be significant at the extremes . . . but not in the middle ranges.' So any difference was only accepted as significant if it was significant over the whole range of the nomograph. Thus, with two populations of 42 and 39, 94 per cent and 79 per cent appear to be significantly different at the 5 per cent level; however, if this difference of 15 per cent is moved to the middle of the range, say to 40 per cent and 55 per cent, the percentages are not significantly different. In this case the difference between the two original percentages, 94 per cent and 79 per cent, would not be regarded as significant.

Significance levels are indicated as follows:

\times = significant at the 5 per cent level

$\times\mathbf{x}$ = significant at the 1 per cent level

\mathbf{xxx} = significant at the 0.1 per cent level.

Appendix II*

GUIDED INTERVIEW SCHEDULE FOR MOTHERS OF CHILDREN (DOWN'S SYNDROME AND CONTROLS) AGED 15 MONTHS

Name

Date

Mother

Not working/part time/full time

Occupation

If working, who looks after the baby?

Father

Hours worked

Saturdays? Yes/No

Feeding

	Age in months												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Breast													
Bottle													
Solids													

* This schedule is adapted from (but not identical with) the 'Guided Interview Schedule for Mothers of Children aged 1 Year' devised by Doctors John and Elizabeth Newson and published in their book *Infant Care in an Urban Community*, 1965, Allen and Unwin.

Does he use a bottle now? Yes/No

What for? Milk Other

How many per day? Times?

Feeding schedule: Rigid to clock/flexibly rigid/flexible/demand

Solids

Feeding willingness: enjoys/passive/difficult/very difficult

Feeding ability:

Feeds self with:

Fingers	Completely	Partly	Not at all
Cup			
Spoon			

What do you do when you prepare something and he won't eat it?
(What would you do?)

Anxious (battles—coaxing every mouthful)

Mildly concerned (much encouragement)

Unconcerned (takes no notice, lets child leave it)

Present non-nutritive sucking

Objects habitually sucked (prompt)

Fingers/thumb/hands/rattle or ring/EMPTY bottle/cloth/dummy

How much? Continually/frequently/occasionally/not at all

Does he have any special time when he sucks things?

Yes/No

Sleepy/hungry/thwarted/other

Have you tried to stop it at all? Yes/No

If so, how?

Did he mind?

Has he ever had a dummy? Yes/No

(If M shows disapproval of dummies, tick here)

Assessment of M's attitude:

..... Intolerant (prolonged restraint or attempts thereat)

..... Semi-permissive (discouragement, mildly dissuasive)

..... Permissive (ignores or encourages habit)

Sleeping Daytime = A Night = B

Where does he sleep?

In own room/sharing with sib/sibs/sharing with adult/in other room/
sharing bed/pram

Do you usually do anything to get him to sleep?

A. During the day?

B. At night?

What do you do if he won't sleep or cries when you have left him?
(What would you do?)

A.

B.

And if he goes on crying?

How much does he sleep in the day?

Do you think this is enough for him?

How often does he wake in the night?

Most nights/more than twice a week/less than twice/very seldom or never

How long does he stay awake?

What do you do if he wakes?

Stay with him/give him bottle in bed/give him dummy/settle him down
and then let him cry/take him into parents' bed/other

Does anybody else ever go to him in the night? Yes/No

How often? Frequently/sometimes/very occasionally

Do you think it does a child of this age any harm to be left to cry?

How long would you leave him to cry if you thought there was nothing the
matter with him?

Behaviour problems and toilet training

Does he ever have temper tantrums?

Frequently/sometimes/seldom or never

What seems to start them off?

What do you do?

How do you punish him when he's naughty?

What sort of naughtiness?

How much does he cry?

Frequently/occasionally/rarely

How long does he cry at any one time?

What about?

What do you do?

Does he ever use a potty?

For wetting: Usually/sometimes/never

For bowel movements: Usually/sometimes/never

If Never to either of these: Did he ever use it?

Wetting: Yes/No Age?

Bowels: Yes/No Age?

When did/will you start giving him the potty?

At what age do you think a child should be dry in the daytime?

Normal

Mongol

At what age do you think he should regularly ask for a potty for bowel movements?

Normal

Mongol

If started training: Are you taking trouble to get him trained?

M very concerned/mildly concerned/unconcerned

Does he play with his body much?

Playing with nose/scratching face/pulling hair/playing with toes/sucking fingers etc./playing with private parts/head banging

If other than sucking: Do you try to stop him at all? Yes/No

If yes: How?

Does he mind?

Father's participation in child-rearing

How much does his father have to do with him?

Does he (mark each category Often (O) Sometimes (S) Never (N))

Feed	Change	Play with	Bath
Get him to sleep	Attend in the night	Take him out with you	

If there are other children: Does father do a lot for some other child?

Do you and your husband ever manage to leave the baby so that you can both go out? Yes/No

How often? Frequently/occasionally/rarely or never

Who looks after the baby?

Paid sitter/relative/friend/other children

Would you like to be able to go out more?

Yes/No

If Yes: Why can't you?

Going out in the day: a = + baby

b = - baby

Frequently

Occasionally

Rarely or never

Visiting

Enjoyment

Household shopping

Would you like to go out more? Yes/No

If Yes: Why can't you?

How much do you have to carry him?

Everywhere in the house/sometimes/never

How heavy do you find him?

Very heavy/quite heavy/tolerable

How much washing do you have to do?

Enormous wash/average/rather little

Do you use disposable nappies at all?

Always/sometimes/never/on holiday

Washing machine:

fully automatic/with spin-drier/electric or gas washer/wash boiler/other

If no machine: How is washing done?

By hand/launderette/laundry/other

Drying: Tumble drier/airer drier/airing cupboard/outside line/inside line/
clothes horse round fire/other

How often do you do washing?

How much of a burden to you is the washing?

Very burdensome/tiresome/tolerable

How much dressing does he do?

Takes off some things/tries to put on some/holds up arms/gives no help

How much has he to be supervised?

Left all morning, occasional visit/keep an eye on him/constant watching
or confinement

Can he be supervised by someone other than you?

Relative/neighbour/sib

How destructive is he?

Very/quite/not very

Does he go for anything in particular?

Paper/books/plugs/flexes

How do you cope with it?

What are the biggest difficulties you have met in handling him?

Do you feel you can cope with these?

Appendix III*

GUIDED INTERVIEW SCHEDULE FOR MOTHERS OF CHILDREN (DOWN'S SYNDROME AND CONTROLS) AGED 4 YEARS

1. Child's name (N)
2. Names and ages of sibs
3. Mother (M)
Not working/part-time + child/part-time—child/full time
Occupation
Who looks after child paid/unpaid
4. Father (F)
Occupation Social class
Previous occupation Social class
Does he have to be away from home at all, except during the day?
Home every night/occasionally away/often away/separate, divorced or
dead
5. Walking
Freely/with help/not
6. Age of walking
7. Feeding
Feeds self entirely/some help/much help/entirely fed

* This schedule is adapted from (but not identical with) the 'Guided Interview Schedule for Mothers of Cerebral Palsied Children' devised by Doctor Sheila Hewett with Doctors John and Elizabeth Newson and published in their book *The Family and the Handicapped Child*, 1970, Allen and Unwin.

16. How much do you mind having to give him this amount of help?
Very much/a bit/doesn't mind at all/N.A.

Sleeping

Illnesses

31. What illnesses has he had?

	Badly	Normally	Mildly	Age
Measles				
Mumps				
Chickenpox				
German Measles				
Pneumonia				
Other				

How much does he tend to get:

	Often	Sometimes	Rarely or never
32. Colds			
33. Coughs			
34. Bronchitis			
35. Diarrhoea			
36. Constipation			
37. Vomiting			
38. Temperatures			
39. Other			

40. Does he take any medicines or tablets regularly? Yes/no
If yes: What is this for?41. Would you say he is rather delicate in his health, or is he a strong child, or is he about the same as most children?
Strong/normal/delicateContacts with father

42. How much does your husband have to do with him? Does he

Bath him?	O / S / N
Dress or undress him?	O / S / N
Read to him or show him a picture book?	O / S / N
Give him his meals?	O / S / N
Change him or take him to the toilet?	O / S / N
Take him out without you?	O / S / N
Look after him while you are out?	O / S / N

Is there anything else that your husband does for him?

Is there anything he won't do, that he draws the line at?

43. Does your husband look after the other children a lot?

Much/some/little/none

What does he do with them? Plays/reads/takes out/homework/other

Rating

44. Father with child Highly/fairly/non-participant

45. Father with sibs Highly/fairly/non-participant
 46. M re F and child Satisfied/dissatisfied/not shown
 47. M re F and sibs Satisfied/dissatisfied/not shown

Contacts with other people

48. Some people say that having a handicapped child makes a mother very lonely. Would you say this was true, from your experience? Yes/no

49. Do you go out visiting at all?

O / S / rarely or never

(Often = 1-2 per fortnight, rarely = 1 per 3 months or less)

Do you take N with you?

O / S / rarely or never

Do people come and see you?

O / S / rarely or never

50. Do you find your friends and neighbours helpful with N?

Very

Quite

No

Many.....

A few, or one.....

51. Do you see much of your relations?

Much

Some

Little

No

Many.....

A few.....

Have they been a help to you with N?

Very

Quite

No

Many.....

A few.....

Do you think they will help you as time goes on? Many/a few/no

52. Have you met any other mothers of mongol children?

Yes/no

If No: Would you like to meet them?

Yes/no

Would you have liked to in the past?

Yes/no

If Yes: Do you find it helpful to meet other mothers of mentally handicapped children?

Yes/no

If Yes: What do you find most helpful about meeting them?

If No: Why not? (prompt) Do you find other mentally handicapped children depressing?

Rating

53. Relatives: None/isolated/adequate/much support

54. Friends: Isolated/adequate/much support

Contacts with social service agencies

Now we'd like to know about other sorts of help you have had with N.

55. Does the Health Visitor from the Clinic call on you to see how he is getting on? Yes/no/not now
If Yes: how often?

56. Has anyone else been to see you?
Regularly Occasionally Welcome Neutral Unwelcome
Health Visitor
N.S.M.H.C.
Health Dept.
Other

57. If any visits: How do you feel about these visits?
Do you find them helpful?

58. If no visits: Have you asked them not to call? Yes/no
If Yes: Did you have any particular reason for not wanting them to call?

59. Would you like more visits? Yes/no
If you had not had Dr Cowie and myself coming regularly to see you would you have liked visits from someone else? Yes/no
If Yes to either: What sort of visits do you think could be most helpful—advice about special problems or just a friendly chat?
Advice/chat/both

60. Does your own doctor take a special interest in N?
Very interested/as much as in other children/uninterested
Have you found him particularly helpful? Yes/no

61. Do you take N down to the Clinic? Yes/no/not now
Do/did you find the people at the Clinic especially helpful? Yes/no
Who especially?
In what way?
If No: Why not?

62. Do you think it would be better if they had a separate clinic for handicapped babies? Yes/no
If Yes: in what way?

63. Do you belong to the local group of the N.S.M.H.C.? Yes/no
If Yes: How did you hear about it?
What branch is it?
How often can you manage to attend meetings? Most/some/seldom

64. Do you find the Society's meetings helpful? Yes/no
In what way/why not
Do you find the Society helpful in other ways? Yes/no

65. Have you ever been to a party, or a meeting with the children? Yes/no
 Did you enjoy it? Yes/no
 In what way/why not?

66. If 63. No: Have you heard about these groups? Yes/no
 If knows: But you didn't join—can you say why not?
 If doesn't know: Would you have joined if you had known about it? Yes/no

67. If you wanted help or advice, other than about his health, who would you turn to?
 G.P./Health Visitor/Mental Welfare Officer/school/N.S.M.H.C./consultant

68. Have you read any books or booklets or articles in magazines, about mentally handicapped children? Books/booklets/articles/none
 If Yes: Any one in particular?
 Did you like them? Yes/no/both
 Have you heard talks on the radio or seen TV programmes on the subject? Radio/TV/none
 Were they easy to understand? Yes/no
 Were they interesting? Yes/no
 Were they helpful to you? Yes/no
 Any one in particular?

69. Has any one suggested that you might go to see a Junior Training Centre? Yes/no
 If Yes: Have you done this? Yes/no
 What did you think of it?
 If No: Would you like to go and see one? Yes/no
 If no: Why not?

School or Training Centre

70. Does N go to a nursery of any sort?
 Day nursery/nursery school/training centre/home

71. What time does he leave home? and get back?
 How many days a week? Full time/part time/none

72. If none: Would you like him to go to one? Full time/part time/no

73. How far away is the school? How does he get there?
 Special coach/public transport/car/walks/other/N.A.
 Is it easy to get him there and back? Yes/no
 If No: What would make it easier?

74. Does he enjoy being there? Yes/quite/no
 Does he get upset when you leave him? Yes/a bit/no

75. Does it help him? Yes/no/doubtful
 In what way?

76. Does it help you?
 (prompt) By suggesting ways you can help him
 By giving you time to yourself

77. Can you go to the school and talk to them about N any time you like
 Often/by appointment or open day/occasionally/no
 Have you done that? O / S / N

Medical Supervision

78. Does N see your own doctor regularly, or only if he isn't well?
 Regularly/only when unwell

79. Does he have to attend a hospital at all? Yes/no/not now
 If Yes or if used to:
 How often?
 Does he always see the same doctor?
 What does the doctor do at these visits?
 Examines N thoroughly/cursorily/discusses with M/other

80. How helpful are/were these visits? Very/quite/not

81. Some people think that it's worth while getting special treatment that you can't get from a hospital. Have you ever thought of trying to get other sorts of treatment or advice from anyone outside the Health Service—a private specialist for instance, or a faith healer? Yes/no
 Have you ever been to anyone like that, who wasn't an ordinary doctor?
 If Yes: When was that?
 Where did you see him?
 How did you hear about this treatment?
 How often did you go?
 How long did you keep going?
 Did you pay for this yourselves?
 How much did it cost you?
 How much good do you think it has done for N?
 Does your doctor know about it?

82. Has your doctor ever discussed with you the question of your having more children? Yes/no
 When was that? Soon after birth/+ 1 year/+ 2 years
 What did he say?

83. Have you discussed this with anyone else? (prompt if necessary)
 Husband? G.P./specialist/husband/relative/friend/other/no one

84. Before N was born, did you want more children after him/her?
 Wanted/didn't mind/didn't want
 And after he was born?
 Wanted more/didn't mind/didn't want more

85. Are you using any birth control methods?
 No/yes
 If No, prompt if necessary: does your husband use any birth control
 method? Yes/no
 How long have you been using that?

Separation from mother

86. Has N ever been separated from you for more than a few days?
 Has he been to hospital or a residential centre at all? Yes/no
Age Place Length of stay Reason

87. If Yes: Were you able to visit him at all? Yes/no
 How often?
 If no visiting: Was that because visiting wasn't allowed, or was there
 some other reason?

88. Would you say that N behaved differently when he came home again—
 was he upset at all? Very/slightly/no/no separation

89. Have you ever been offered short-stay accommodation for him?
 While you have a holiday for instance? Yes/no
 Have you ever done this? Yes/no
 Where?
 Did he enjoy it?
 Did you enjoy it?
 How was he when he came home?
 Would you like to do this again?

90. Have you ever had to go away from him—to hospital or anywhere else?
Age of child Length of separation Reason No
 How was he looked after during this time?
 At home/relative/nursery or hospital
 Was he upset by this at all? Very/slightly/no

91. How has your own health been since N was born? Good/fair/poor
 Specific complaints:

92. Do you find that you get very run-down or depressed?

Depressed/run-down/no

If Yes: Have you had any treatment for this?

Sleeping tablets/tablets/visit to psychiatrist/other/none

Management of child

I'd like to know something of how you manage to fit in your housework with looking after N.

93. Does anyone give you any help with the housework? Yes/no

Who?

Paid/unpaid

How often?

Often (3 days per week +)/occasionally/rarely

94. What about shopping—do you take him with you? Yes/sometimes/no

If No: How do you manage your shopping?

95. Do you find that other mothers stop and talk to you about N, and take an interest in him? Yes/sometimes/no

Some mothers of handicapped children say that that's something they don't like. How do you feel about it?

96. Do you take him on other outings (with the other children) to the park for instance, or anywhere else? Yes/sometimes/no

97. About how long can you leave him in a room on his own while you get on with other things? Few minutes/< $\frac{1}{2}$ hour/ $\frac{1}{2}$ hour or more

How long will he amuse himself without wanting your attention?

Few minutes/< $\frac{1}{2}$ hour/ $\frac{1}{2}$ hour or more

98. What does he like doing best—what is his favourite occupation?

99. What toys seem to give him the most pleasure?

99A. What toys have you got specially for N?

A. Puzzles

B. Swing

Bricks

Slide

Hammer Peg

Climbing

Fitting cups

Jumping

Screw-up toys

Rocker

Pull-along

Walker

Other

Tricycle

Other

C. Miscellaneous (dolls, teddies, etc.)

99B. Do you usually play with him with these, or does he usually get on with them by himself?

Often plays with N/sometimes plays/rarely or never plays

99c. What have you tried to teach him?

1. To do

2. To say

Counting

Colours

Alphabet

Names

Other

3. To sing

100. Do you keep any pets? No/yes

Is N particularly fond of the

Yes/no

Is he safe with it—(will it hurt him?)

Yes/no

Is it safe with him—(will he hurt it?)

Yes/no

101. Is he a happy child, or is he miserable a lot of the time?

Happy/varies/miserable

102. Does he want a lot of cuddling? Much/same as most/less

103. Would you say he is an easy child to manage? Easy/same as others/ problem

If problem: What is the main problem with him?

104. Does he ever have a real temper tantrum? Often/occasionally/rarely or never

What does he do?

What starts them off?

Do/have/taken/teased

How do you deal with it?

Sort/distract/ignore/isolate/scold

105. Would you say he gets in as much mischief as most children of his age? More/same as most/less

What kinds of mischief?

Do you think he does these things on purpose? Yes/don't know/no

106. What sort of things upset him?

How do you cope with it?

Discipline107. Children of this age often don't want to do as they are told. What do you do when this happens with N? (Not dangerous situation)
If sibs: Do you do this with the other children too or do you find that you have to try to manage N differently from them? Same/different

108. If he refuses to do something that he really must do, what happens then? (If M says 'I make him', prompt: How?)

109. Do you ever promise him a reward for being good?
 Yes/occasionally/no
 What sort of goodness?
 What sort of reward?

110. How do you feel about smacking? Do you feel it's necessary to smack most children? Yes/occasionally/no
 And N? Yes/occasionally/no

111. Do you smack N *simply* as a punishment, or do you have to be really angry and at the end of your tether? Punishment/angry/both/neither

112. What sort of naughtiness do you usually smack him for?

113. On the whole, do you think smacking does him good? Yes/no
 (Prompt: In what way?)

Rating

A. Smacks only as punishment/in anger/both/almost never
 B. M believes in smacking/disapproves
 C. Excludes N because of handicap/makes no difference between N and sibs/no sibs

114. Is there anything else you do when he is naughty?
 (115-119: If M says 'Never' to any of next 5 questions, ask after each: 'Would you if he were not handicapped?')

115. Do you ever send him to bed, or put him in a room by himself as a punishment? Yes/would/no

116. Do you ever say he can't have something he likes—sweets or TV or something like that? (as a punishment) Yes/would/no

117. Do you ever tell him that you won't love him if he behaves like that? Yes/would/no

Omit if child is present

118. Do you ever say that you'll send him away, or that you'll have to go away from him if he is naughty? Yes/would/no/omitted

119. Do you ever threaten him with someone else—his Daddy for instance, or the doctor? Yes/would/no

120. *If child talks:* Do you think it is important for him to say sorry when he's done something wrong? Do you ever make him do that, even if he doesn't want to? Yes/no/N doesn't talk

121. *If other sibs:* Do you think you make more allowances for N than you do for the other children? Yes/no

If Yes: Do they understand that this can't be helped, or do they think that he gets away with things, and that this isn't fair?

Understand/resent

122. Do the other children ever seem jealous of N for the attention he gets?
Yes/occasionally/no

I think where there's a handicapped child the other children often do feel a bit left out. What do you think about this problem?

123. Do you have much trouble over the other children's behaviour generally?
Yes/no

If Yes: In what way?

124. On the whole, are you happy about the way you handle N's behaviour, or do you find yourself doing things you don't really approve of?
Happy/fairly happy/unhappy

125. Do you agree with your husband about this, or is he a lot more strict or less strict than you are? F more strict/agree/F less strict

126. Do you and your husband always agree about how N should be brought up generally, or do you feel differently about some things?
Always agree/often agree/seldom agree

Leisure Activities

127. Have you had a holiday since N was born? 2+/1 only/none
If Yes: Did you all go? Whole Family/-N/-sibs/-F

1st holiday

2nd holiday

3rd holiday

128. Was it a success? 1st—yes/no; 2nd—yes/no; 3rd—yes/no

129. If N taken with family/parents: Did you find your accommodation yourself? Yes/no

130. If no holiday: If you could have left N in good hands for a few days, would you have gone without him? Yes/no

131. Would you let him go to a residential centre so that you could have a break? Yes/no

132. Suppose you had to go away unexpectedly—into hospital or something like that—what arrangements would you make for N?
F take time off/other relations or friends/institution

133. And for the other children?

F take time off/other relations or friends/institution/look after themselves

Babysitting

134. Do you and your husband ever manage to leave N/the children so that you can go out together? 1+ per week/1+ per month/seldom/1 or less per year

Would you like to go out more than this? Yes/no

135. What happens when you go out? Does someone come in? Do you pay her? Paid sitter/grandmother/other relative/friend/or neighbour listens/other children responsible/nobody responsible

136. Do you ever go out without your husband, in the evening? Yes/no
Does he ever go out without you? Yes/no

137. Do you ever go out in the day and leave N with someone else for a while? (exclude school and M's work if any)
2+ per week/1-2 per fortnight/occasionally/never
About how long do you leave him?
What is the longest time you feel you can leave him for?

138. How does he seem if you leave him with someone? Does he mind you leaving him? Yes/a bit/no
If Yes: What do you do about that?
If No: Was there ever a time when he minded? Yes/no
What did you do about that?

139. Do you always tell N when you are leaving him, or do you find it easiest to slip off without his knowing? Always tell/usually tell/don't

140. If there are sibs: Does it make a difference if he is with the other children when you leave him? Better/no difference/worse

Attitude of other sibs to N

141. Does/do the other children bring their friends home to play? O / S / N
If Yes: Do they take an interest in N? Do they talk to him at all? Yes/no

142. Do the children include N in their games at all? Yes/no/N.A.

143. Has he any friends of his own, children who come in to play specially with him?
Ages? Normal Handicapped No
.....
How often? Most days/1 per week/less
How did he make this friend?
Can they be left on their own to play? Left/some supervision/much
What do they play?

144. When the other children go out to play, in the street or the park for example, do they ever take N with them?
 O / S / N /sibs too young/too old

145. Does N ever go out to play in other children's houses, or in the park or in the street, with other children? O / S / N

146. What do you do if he gets in a disagreement or quarrel?

147. In general, do you find it possible to leave N to settle his own differences at this age? Always/often/seldom/N.A.

148. Suppose N complains to you of another child, what do you do?

149. Does he ever hit another child back? Yes/no
 Do you encourage him to stand up for himself in this way? Yes/no
 If No: Is there any situation in which you might do that?

150. Does N do his own share of starting quarrels? Does he tease the other children? Yes/no

Rating Encouragement of aggression in self-defence
 General encouragement/special circumstances/never

Child's behaviour
 aggressive/adequate/passive

Looking ahead

151. At the moment, who do you rely on most for help?
 (if husband)—and who after him?

152. Can you think of any kind of help you would have liked that you haven't had?

153. Do you ever try to make plans for N, for the future, or do you face each day as it comes?

154. Have you any suggestions to make that might be helpful to other mothers of handicapped children—either practical suggestions for looking after their children, or on how you manage to face this and come to terms with it?

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Young Children with Down's Syndrome

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CAR

The book covers the developments, up to the age of 4 years, of children with Down's Syndrome, their upbringing and effect on family life. Two matched groups of children were studied, one of normal children, the other of Down's Syndrome children. The children were visited and given developmental tests at specific times and their mothers were interviewed.

The first part of the book describes the development of the children as indicated by the test results; the second part describes the results of the interviews with the mothers and explores the problems encountered by families with a young, mentally handicapped child.

It is primarily aimed at the professions concerned with mental handicap—psychologists, doctors, social workers and teachers—but will also be of interest to parents of children with Down's Syndrome.

CONTENTS: Down's Syndrome—Implications of the Diagnosis. Populations and Procedures. **SECTION I: THE DEVELOPMENTAL STUDY.** Results from Developmental Testing. **SECTION II: THE FAMILY STUDY.** Problems of Everyday Life. Behaviour and Discipline. The Effect on Family Life. Social Life for the Family and Community Contacts. Help for the Families. The Effects of Social Class. 15 months to 4 years. A Longitudinal Comparison. Conclusion. Appendices: Statistical methods used. Guided interview schedule for mothers of children (Down's Syndrome and Controls) aged 15 months. Guided interview schedule for mothers of children (Down's Syndrome and controls) aged 4 years.